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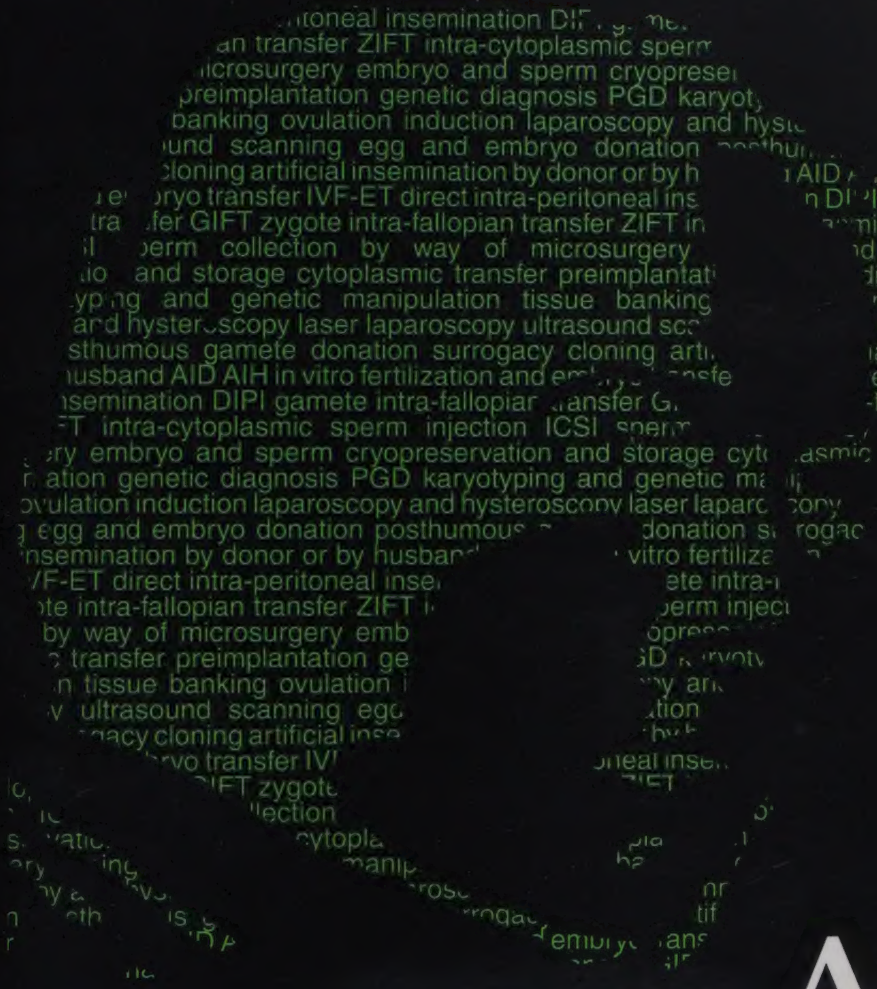

ARTs and Women

Assistance in Reproduction or Subjugation?

A study by Sama

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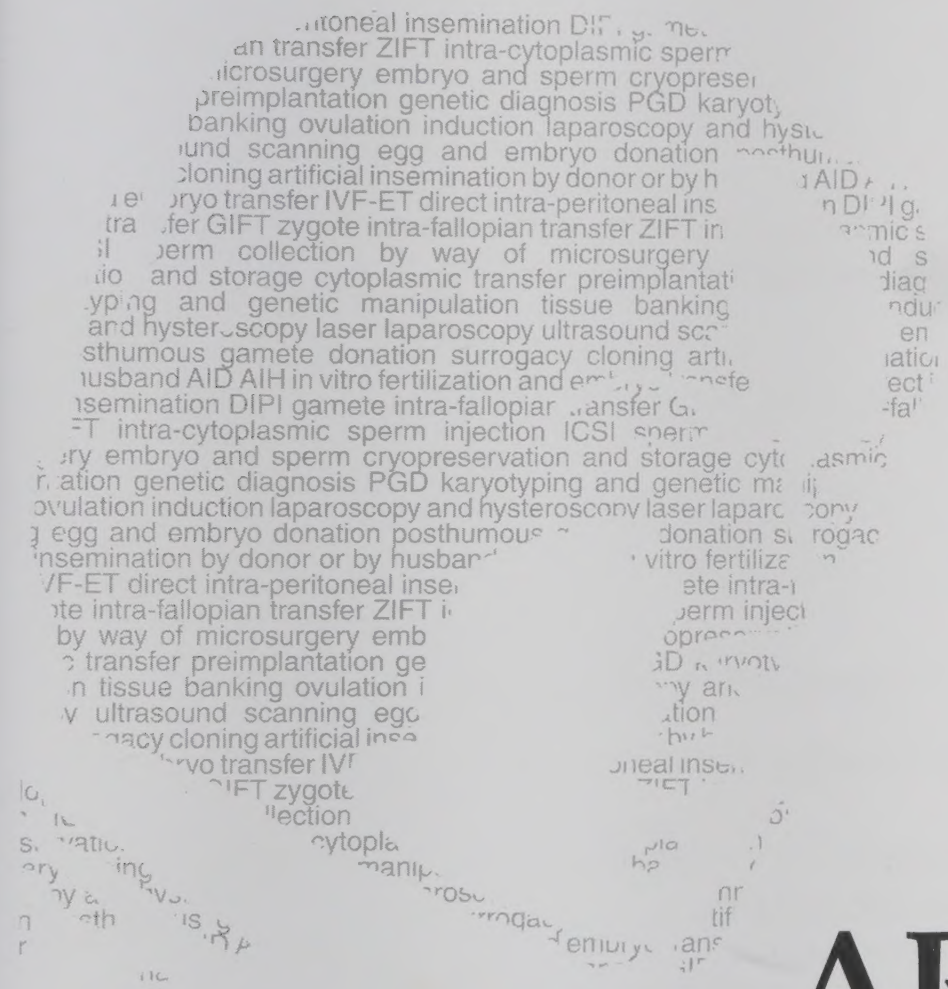

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Introduction

One of Sama's [1] primary concerns, from its very inception, has been to raise a voice against the prevailing anxiety about population growth and the coercive measures advocated by the State to control population. The state's policies invariably target women, especially those from marginalised communities. Sama initiated a study in 12 districts in Madhya Pradesh in order to understand the implications of the two-child norm on the participation of people especially women from marginalised communities, in institutions of local governance.[2]

As part of the health movement and the autonomous women's movement, Sama has also repeatedly campaigned against technologies that target women's bodies to either assist birth, control birth or facilitate the determination of the sex of the foetus. This has ranged from carrying out research on the health risks of injectable contraceptives like Depo-Provera[3] to campaigning against the introduction of Depo-Provera and NET-EN in the family planning programme. We oppose these contraceptives because they have been developed through unethical research; there is no conclusive information about their efficacy, and there is evidence of the fact that these technologies have long-term risks.

In the course of our involvement in the campaign against contraceptive technologies and coercive population policies, we came to understand that conceptive (or "assisted") technologies lie on the same continuum as contraceptive technologies. The similarity derives from the fact that both these technologies target women's bodies by intervening and altering the physiological processes.

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1 Sama-Resource Group for Women and Health is a Delhi based Organisation working on issues of health from a larger perspective integrated with livelihood, violence (societal, familial, communal and medical), and all other issues that affect people's lives, especially those of women.

2 Beyond numbers, Implications of the two-child norm, Sama. 2005.

3 Unveiled realities- a Study on Women's Experiences with Depo-Provera, an Injectable Contraceptive, Sama. 2003.

Scientific and technological interventions to prevent those who can have children from having them, and to enable those who cannot have them, are the two ends of this continuum. Both these technologies target women's bodies and take control of their reproductive potential.

Our research on Assisted Reproductive Technologies was guided by the perspective that the relationship between reproductive technology and its end user is governed by gender and further compounded by caste, class, religion, ethnicity, sexual orientations and other social relations of power. As long as these underlying currents are not identified, the concepts of choice, empowerment and rights are merely words to be written on paper and these technologies will go on propagating a gender bias in general and towards women's health in particular. We felt strongly that we had to take up the issues raised by ARTs. The emphasis of the research was to gain an insight into the social, medical and ethical implications of ARTs, especially on women, as they raised important issues at the societal level and therefore demanded serious reflection, investigation and debate. However, while searching for material, analyses and perspective on conceptive technologies, we found that the issue had not been adequately addressed in the Indian context. With this understanding and this lacuna in mind, we felt the need to delve into the ART industry that has been gaining ground with each passing day.

For us, the research was important because we wanted to give voice to women's own experiences and their perceptions of fertility control and place women's decisions within the context of their family dynamics and their social realities.

The report "ARTs and Women; Assistance in Reproduction or Subjugation?" consists of seven chapters, which are based on our research findings and their subsequent analysis.

Chapter One describes the context that has led to the growth and proliferation of ARTs. It touches upon the various facets of the international feminist discourse and debates around the issue of ARTs. There is also a discussion on the medicalisation of infertility and the consequent implications on the status and role of women, especially in the Indian context. The language used in the medical discourse in order to promote infertility and, consequently, ARTs, is also examined. The history of ARTs in India, including their transition from the public to the private health sector, is outlined.

The Second Chapter lays down the objectives of the research, the methodology adopted, the areas of study, gathering and analysing data, ethical considerations and various constraints and limitations faced during the research.

Chapter Three comprises a detailed account of the fieldwork of the research. A brief profile of both providers and women undergoing these procedures is given. The study findings are categorised as responses and perceptions of the providers on the one hand, and perceptions and experiences of the women on the other. The social implications of ARTs on the lives of women are highlighted here.

Chapter Four talks of the increasing commercialisation of the ART industry in India and its implications for women, with primary focus on the fragmentation and commodification of women's bodies.

Chapter Five addresses the responses of the various progressive movements in India, to the issues raised by ARTs.

Chapter Six reviews the guidelines proposed by ICMR for the ART regulation of the industry in India, juxtaposing it with the ground realities highlighted by the study.

In Chapter Seven, we have attempted to reiterate some of the major issues concerning ARTs that were raised in the preceding chapters, and to sum up the various ways in which these technologies affect the lives of women.

CHAPTER 1

The context

The last two decades have been witness to a rapid increase in the number of technologies that assist reproduction, increasing the chances of conception and carrying a pregnancy to term. Collectively these are called Assisted Reproductive Technologies, or ARTs. They encompass various procedures ranging from the relatively simple Intra-Uterine Insemination (IUI) to variants of *In-Vitro* Fertilisation (IVF), more commonly known as "test-tube baby technology". Although ARTs are often referred to as "new" reproductive technologies, they have existed as early as in the 16th century.[1] Artificial insemination in humans has been practised from the 1870s. However, since the latter half of the 20th century these technologies have developed at a rapid pace, affecting the way that society views reproduction, pregnancy, and motherhood. This "new" phase can be traced back to the birth of Louise Brown, the world's first IVF baby, born in Oldham, Lancashire, UK, in 1978 under the "care" of Dr. Robert G Edwards and Dr. Patrick Steptoe.

However, this new milestone raises a number of complex issues that emerge from the links between health, society and technology. ARTs may do more than just help women satisfy their desire for motherhood; they will also influence their lives too. This is especially true in the prevailing twin contexts of patriarchy and market forces. In this scenario, it is necessary to re-examine the interconnectedness between social structures, the scientific establishment and the market, and their impact on the creation and proliferation of ARTs. This is particularly important given the two-way relationship between science and social norms; science is both shaped by social mores and works to reinforce them. It is therefore of fundamental importance to understand the synergetic relations between scientific research and the social pressures relating to motherhood.

In order to see the complete picture, it is important to view the "new" reproductive technologies within the context of the politics behind scientific research interest and perceived social pressures towards motherhood. Women in this situation become doubly disadvantaged as they suffer both from the prevailing patriarchal hegemony

1 See for example, Gena Corea, The Mother Machine: Reproductive Technologies from Artificial Insemination to Artificial Wombs. New York: Harper and Row, 1985.

and those created by the "medicalisation of everyday life". As, in the words of Maria Mies, we tend to forget the "historical fact that technological innovations within exploitative and unequal relationships lead to an intensification, not attenuation, of inequality, and to further exploitation of the groups concerned."[2]

The issues raised by ARTs are so complex and double-edged that feminist discourse over it is divided. Martha Gimenez outlines some of the dominant paradigms of feminist thought on the issues of ARTs[3]. In her words, "...some writers stress the role of patriarchy in oppressing women through New Reproductive Technologies, while others stress the interaction between patriarchy and capitalism. Regardless of theoretical orientation, feminists share a common concern with the fact that these technologies have undermined hitherto taken-for-granted relationships between biology, women's identity, and the meaning of motherhood." Thus, while some feminists critique the technologies as embodying a patriarchal and pronatalist agenda, others argue for a more nuanced view which incorporates women's agency and a wider social understanding of reproduction and the social, political and economic influence surrounding the development and use of these technologies.

Some others, like Gena Corea[4] have voiced the need for a total rejection of modern conceptive and prenatal technologies because they are perceived as reinforcing existing unequal social relations. "Far from enhancing women's reproductive choices," feminist critics argue, "these technologies place women under male control." We find varied opinions on this among feminists, with some claiming these technologies to be emancipatory in nature whereas others see these technologies as an instrument in the hands of capitalism and patriarchy, reducing women's role only to reproduction, thereby furthering their subordination and exploitation. FINRRAGE[5] considers New Reproductive Technologies "a manifestation of patriarchal domination and exploitation of women's bodies by men who envy women's procreative power." As Farida Akhter, a member of FINRRAGE, puts it, "...it is not merely a question of who controls it (ARTs). We have already found that the technology itself is racist, sexist and eugenic in nature."

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2 Maria Mies, "New Reproductive Technologies: Sexist and Racist Implications," Quilt, (Asian Women's Human Rights Council, 1994). pp 41

3 Martha Gimenez, The Mode of Reproduction in Transition – A Marxist-Feminist Analysis of The Effects Of Reproductive Technologies, in Gender and Society, Volume 5, No. 3, September, 1991, pp 334-350.

4 Gena Corea, The Mother Machine: Reproductive Technologies from Artificial Insemination to Artificial Wombs. New York: Harper and Row, 1985, pp167.

5 Feminist International Network of Resistance to Reproductive and Gender Engineering, founded in 1984.

Some feminists welcome these technologies as scientific and technological progress, believing it is the context that makes them good or bad. They base their critique on the recognition that they satisfy some women's legitimate needs. Shulamith Firestone feels that these technologies have the potential to liberate women from the burden of motherhood and hence act as an instrument through which women's emancipation can be achieved.[6] For this group, these technologies are seen as providing solutions for individual women in a context where infertility and childlessness result in social ridicule.

The feminist discussion on ARTs, especially by the group that is critical of them, has focussed a great deal on the language used in the medical discourse in referring to ARTs. This has received a great deal of attention because this language has been deployed as a means of justifying intervention in the female body through ARTs. This language, when closely examined, also reveals the dominance that these technologies seek to exert over women.

ARTs are promoted in the language of benevolence and altruism. The attempt is to instil a false consciousness of goodwill in all those involved in the process of "assistance". The provision of eggs, sperm and even the womb is clothed in the terminology of donor and donation, and doctors are elevated to the status of "miracle providers" who enable "desperate" women to conceive. The reference to a procedure as GIFT[7] is a glaring example of this attempt at seeing it as benevolence.

A closer examination of the language of the medical (here specifically ARTs) discourse reveals the depersonalisation of women. Women are represented primarily by their "cycles" of assisted fertilisation. They are made visible only through their organs that are involved in the fertility treatment, and their "uterine cavity". Women's experiences of the painful intrusive procedures are described as "assisted hatching and fragment removal"[8], and "egg harvesting". One well-known IVF specialist casually confirmed that a woman who was under the IVF procedure "gave five eggs" in one cycle. Such references only in terms of embryos, eggs, oocytes etc, completely depersonalise women.

Intrusion into and experimental invasion of the female body by these technologies is spoken of in terms of "treatments" and "cures" that a woman can "choose" from a

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6 Shulamith Firestone, The dialectics of sex, New York: Bantam Books. 1971.

7 Gamete Intra Fallopian Transfer.

8 Orly Shachar, The Invisible Female Patient: The New Reproductive Technologies Discourse in the Medical Literature.

basket of existing options. Extracting and keeping the ovaries alive and "mining" them for eggs is presented as a boon to women, as "therapy".[9]

Thus, the seductive pitfalls of ARTs are many and manifest most clearly through the language used to describe them. The fundamental dilemma in discussing ARTs, therefore, is how to view them. Should we look at them favourably, for allowing women to express their reproductive needs despite their or their partners' biological condition, and despite their single or homosexual status? Or should they be viewed unfavourably, as yet another patriarchal ploy to reinforce the "norms" of women as mothers, and especially as mothers of sons — a reinforcement of the oppressive notion of "family"? One should answer these questions on assisted conception techniques within the socio-cultural normative framework of infertility and societal response to it.

Infertility and medicalisation

"They claim it all started with infertility – thousand(s) of desperate couples clamouring for the technology to have babies. But it really started with the technology itself. On the first day, reproductive experts created the technology of in vitro fertilization: on the second day, the script of infertility."

—Janice Raymond[10]

Advances in medical science, including ARTs, reflect the existing social context and incorporate social arrangements and power relations. In a patriarchal society such as India's, child bearing and motherhood are glorified, albeit only for married women. Failure to perform this role for whatever reason, makes the couple, especially the woman, vulnerable to stigmatisation, social ridicule and even ostracism. Often, this social pressure is internalised, giving rise to intense feelings of guilt and shame on the part of the couple for not being able to perform the "normal" and "expected" role. What is striking, however, is that although infertility affects both men and women, it is usually the woman who is blamed for childlessness. This reasoning emerges from a patriarchal belief system that treats reproduction as a woman's responsibility. Moreover, women are essentialised; they are nothing more than their reproductive role, not merely as child-bearers, but as bearers of sons, who will then propagate the *vansh*, or the family lineage. A study on infertility[11] argues that infertility threatens the social acceptability of a woman, her legitimate role of a wife, her marital stability,

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9 Gena Corea, The Mother Machine: Reproductive Technologies from Artificial Insemination to Artificial Wombs, New York: Harper and Row, 1985, pp 278.

10 Janice Raymonds The production of fertility and infertility: East and West, North and South, in Women as Wombs, Harper Collins, 1993.

11 Study by M. Prakasamma, quoted in, In Other Words, unpublished document, Sama 2006.

security, bonding and her role in the family and community. The woman also goes through a cycle of denial- treatment-frustration-resignation that leads to emotional strain. This study also emphasises that "infertile" women are not considered feminine. Thus, "motherhood" is central to the social construction of a "woman" and therefore, childlessness is a crisis of a social nature. It is in this overtly patriarchal social context that infertility threatens the social status of a woman, both in the family and the community and sometimes even in her marriage. Since motherhood is central to the social construction of womanhood, childlessness is a social crisis that cheats childless women of their fundamental identity. Given this epitomising of motherhood, one can understand why women who fail to bear a child often subject themselves again and again to the long drawn and often perilous procedures of ARTs rather than adopt a child, or not being a parent.

These procedures are both physically painful and psychologically, emotionally stressful, but there is no escape since technology is the "promised" instrumental manipulation that will coax women's bodies into reproductive performance. Moreover, the idea of ownership; that a woman's womb is the property of her husband and hence the "product" i.e. the child, belongs to the husband, diminishes women's agency to the extent that the woman may often say, "It has to be his (husband's) sperm, I don't care whose egg it is." In such a situation, a woman's right to her bodily integrity stands to be completely violated, since the woman who is required to undergo the treatment may not be opting for it voluntarily.

Scholars like Janice Raymonds are of the opinion that it is wrong to consider and portray infertility as a disease. As traumatic as the absence of children may be for some people, infertility is no more a disease than is the absence of other physical capabilities. Yet, people continue to act as if infertility is a disease, encouraged by a techno science that treats it as such by medicalising infertility at primary cost to women.[12] In fact, the discourse moves a step further and institutionalises infertility as an "epidemic" which must be addressed before it goes out of control. It is in this translation that women are labelled as "patients" and are thus obliged to go through the ordeals of "treatment". This provides justification and reason for expensive treatment of an otherwise healthy body. What is ironic, however, is that these technologies cannot treat the underlying causes of infertility; they merely bypass it and assist reproduction. Infertility in this socio-political context "becomes the new buzzword, and technology the new instrumental manipulation that coaxes women's bodies into reproductive performance. Technological reproduction has made

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12 Janice Raymonds, The production of fertility and infertility: East and West, North and South, in Women as Wombs, Harper Collins, 1993.

medicalised access to the female body acceptable, and medicalised abuse – that a woman will endure anything to become pregnant – standard treatment".[13]

Thus, infertility is created and commodified as a medically manageable problem and once the disease of infertility is established, various technologies are deployed for its treatment. In addition, procedures like IVF are incorrectly publicised as established and successful therapies rather than as an experimental and largely research and development-oriented business.

The potential for exploitation through ARTs is great in a country like India where, "fertility defines womanhood and womanhood is defined by a woman's capacity to mother."[14] The proof of fertility is closely related to status and prestige, respectability and to the very recognition of a person as a woman. Given this paradigm which defines what it means to be a "normal" woman, childlessness brings with it multiple forms of social exclusions. The context being such, in most cases, alternative parenting or for that matter voluntary childlessness, far from getting equal weightage with that of biological parenthood, does not even have the space to exist in this social structure. The social parameters therefore prepare the ground for the introduction and propagation of ARTs in India.

The argument that infertility was "created" to bolster the use of ARTs is further strengthened if we look at the frequently changing definition of infertility. Prior to 1975, a couple was declared infertile if they did not conceive after five years of unprotected coitus. In 1975 however, the World Health Organisation (WHO) reduced the time to two years and by 2005, reduced it further to one year. The ICMR guidelines[15] define infertility as "failure to conceive after at least one year of unprotected coitus." This expanding definition has strengthened the claims of the medical establishment and other vested interests, both scientific and economic, that there is a virtual epidemic of infertility. It has also increased medical interventions into women's reproduction. Given this definition of infertility it is difficult to ascertain the exact figure of infertility and there is a probability that more and more couples will be marked as infertile for their temporary childlessness. WHO states that 8 to 12 per cent of couples around the world have difficulty conceiving a child at some point in their

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13 Janice Raymonds, Reproduction, Population, Technology and Rights, Women in Action, Vol. 2, 1998.

14 Anjali Widge, "Sociocultural attitudes towards infertility and assisted reproduction in India", in EffyVayena, Patrick J. Rowe and P. David Griffin (eds.), Current Practices and Controversies in Assisted Reproduction, WHO, Geneva, 2002, pp. 60-74.

15 ICMR, National Guidelines for Accreditation, Supervision and Regulation of ART Clinics in India, 2005.

lives, "thus affecting 50 to 80 million people.[16]" Between 23 and 60 per cent of women who undergo IVF treatment do so because of their male partners' infertility.[17]

A multinational study done by WHO, that included India, places the incidence of infertility between 10 and 15 per cent of the total population. Out of a population of 1,000 million Indians, an estimated 25 per cent (250 million individuals) may be conservatively estimated to be attempting parenthood.[18] A village-based study in the State of Maharashtra puts the level of infertility at 6 to 7 per cent. The National Family Health Survey (NFHS) conducted during 1998-99, claims that 3.8 per cent of women between the ages of 40 and 44 years have not had any children and 3.5 per cent of currently married women are declared "infecund".[19] In order to have a better understanding of infertility, one should also look at how infertility has been dealt with and approached in various health policies and programmes. It is debatable that, as in many developing countries, in India too, infertility treatment is not part of the reproductive health services offered. The issue of infertility has not been an area of focus of the public health programme of the Government of India. This is in spite of the fact that the Government of India is a signatory to the programme of action of the International Conference on Population and Development (ICPD). This programme states that reproductive health services should include prevention and appropriate treatment of infertility. However, national policies and other programmes have largely ignored the issues of infertility. Though the Ninth Five Year Plan (1997-2002) of the Government of India has included infertility in the comprehensive Reproductive and Child Health programme (RCH), the primary health care structure has not been able to convert it into reality. A study by Alexandar and Apte (in 2002) clearly points out the limitations and shortcomings in the facilities for infertility management in the public health care delivery system in Maharashtra.[20]

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16 World Health Organization. Infertility: a tabulation of available data on prevalence of primary and secondary infertility. Programme on Maternal and Child Health and Family Planning, Division of Family Health, 1991 cited in Abdallah S. Daar, Zara Merali ,Infertility and social suffering: the case of ART in developing countries, in Effy Vayena, Patrick J. Rowe and P. David Griffin (eds.) Current Practices and Controversies in Assisted Reproduction. WHO, Geneva, 2002. (http://www.who.int/reproductive-health/infertility/11.pdf)

17 Fraser, "Male Infertility," http://www.ncbi.nlm.nih.gov/entrez/query.fcgi/cmd.

18 ICMR, National Guidelines for Accreditation, Supervision and Regulation of ART Clinics in India, 2005.

19 WHO, Special Programme of Research, Development and Research Training in Human Reproduction, Ninth annual report. 1980; Report of the meeting on the prevention of infertility at the primary health care level, 12–16 December, 1983 Geneva, World Health Organization, 1984 ; Bang RA et al. High prevalence of gynaecological diseases in rural Indian women. Lancet, 1989, National Family Health Survey 1998–99, India. International, Institute for Population Sciences, Mumbai,2000 cited in Anjali Widge, "Sociocultural attitudes towards infertility and assisted reproduction in India", in Effy Vayena, Patrick J. Rowe and P. David Griffin (eds.) Current Practices and Controversies in Assisted Reproduction 2002. (http://www.who.int/reproductive-health/infertility/11.pdf)

20 Alexander M, Apte H. Are we geared for management of infertility? A study of public and private health facilities in Maharashtra, India Paper presented at the International Conference on Socio Medical Perspective on Childlessness, Goa, India, 2002

Though there is a lack of epidemiological data to support the claim that infertility is on the rise, in common and anecdotal understanding, infertility is portrayed as the new impending epidemic through the medical establishment and the media. This medicalisation of childlessness and its transformation to a state of disease is part of the larger politics behind commercialisation of both fertility and infertility. Whereas, earlier it was possible to draw watertight compartments with infertility being the concern of industrialised countries of the West and the North, and fertility being the concern of reproductive experts in the East and in the developing South, it is not so anymore. Such compartmentalisation still might be valid at a national level in the case of India where population control becomes the sole concern of the State, but there are also simultaneous mechanisms in place to market and medicalise infertility in the individual context as well. This has directed the State on the one hand to equate population control to reproductive health in State initiated programmes and policies, and on the other, to provide the space for fertility treatment to bloom in the unregulated private sector for people who can afford it.

Although infertility represents a small facet of the entire scope of reproductive services, couples who are infertile and access ARTs represent the mainstay of the practice. We often tend to forget that though ARTs are seen as treatments for a disease, they never try to treat the underlying causes of infertility; they merely bypass them. This attempt at a "quick technological fix" not "addressing underlying macro-epidemiological causes of infertility— environmental pollution, workplace, toxicity, iatrogenic factors and untreated or undiagnosed pelvic inflammatory diseases"[21] points towards the politics of scientific research. Moreover, this pronatalist environment is given a further boost, as these procedures are very economical in India, thereby making it a lucrative destination for medical tourism, especially related to ARTs.

ARTs in India

The first IVF baby in India may have been born just a few months after Louise Brown. A Kolkata fertility specialist claimed to be responsible for the second IVF baby in the world, Durga. Dr Subhas Mukherjee's claim was not recognised, due to lack of peer review and scientific documentation. On August 6, 1986, India's first "scientifically documented" IVF baby, Harsha, was born through the collaborative efforts of the National Institute for Research in Reproduction (NIRR) and the King Edwards Memorial hospital (KEM), Mumbai.[22] Dr. Indira Hinduja from Bombay Municipal

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21 Dion Farquhar, "Reproductive Technologies Are Here to Stay", Sojourner20(5):6-7, January 1995, http://www.hsph.harvard.edu/rt21/procreative/Farquhar.htm

22 ICMR, National Guidelines for Accreditation, Supervision and Regulation of ART Clinics in India, 2005.

Hospital and Dr TC Anand Kumar from the NIRR are regarded as the "brains behind the test-tube baby project in India",[23] both in scientific/medical circles and in the media.

The Family Planning Discourse

This initiative has been programmatically linked with the government's concern with population control. Such a rationale has been explicitly stated in the ICMR Bulletin:

" In India, tubal sterilisation is a widely used method for control of fertility. However, due to high infant and child mortality, several women who have undergone tubal sterilisation do seek tubal recanalisation...

...IVF/ET requires comparatively less surgical intervention than tubal recanalisation. If a couple is convinced that pregnancy could be achieved with certainty by the IVF/ET technique, in the event of their losing the existing children, they might readily accept tubal sterilisation as a method of family planning. Thus in vitro fertilization could be of great relevance to our national family welfare programme."[24]

This view was also reiterated in our personal communication with a senior scientist in NIRR, who stated that, "ICMR had initiated research on ARTs at NIRR in the eighties. Family planning was the main concern and there were many coming for reversal of sterilisation to conceive a child. It was felt that IVF would be a better option than recanalisation. This is the logic behind initiating research on these technologies. We collaborated with KEM hospital, which is run by the Mumbai Municipal Corporation, for the research. In 1989, the first GIFT baby was also born at NIRR." In fact, Dr TC Anand Kumar, then from the NIRR, has been quoted as saying: "An understanding of (IVF – ET) may provide clues as to how to induce infertility in fertile couples as a means of family planning".[25]

This idea behind the promotion of IVF and its conceptual linkage with contraceptive technology is not limited to India alone. In the opening speech at The International Population Union Conference on the Scientific Study of Population, held in London in 1969, the "unobstructed vision for IVF" was summed up as, "There are grounds for hoping that the use of IVF embryos for research will lead to the discovery of efficient new methods of population control. This is the real justification for promoting and

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23 Aditya Bharadwaj, 'How some Indian baby makers are made: media narratives and assisted conception in India', Anthropology and Medicine, Vol. 7, No. 1, 2000.

24 ICMR Bulletin,Vol.14, No.10, October 1984.

25 Janice Raymonds The production of fertility and infertility: East and West, North and South, in Women as Wombs, Harper Collins, 1993.

funding of IVF by governments and organisations involved in population planning."[26]

Growth Potential of ARTs

Though the ICMR was very keen to carry forward its zeal to develop newer techniques, it had to discontinue it for various reasons. "Lack of funds was one of the main reasons. Moreover, NIRR, is a research institute and not a service providing centre or public hospital".[27] What started as a government initiative later fed into the private sector and ART has since then flourished as a private industry in India. The potential market for infertility treatment is estimated conservatively at 25,000 crores[28] in the private sector as these services are not available in public hospitals. The ART industry has been on a steady rise since its introduction in India. According to the ICMR, "There are an estimated 250 IVF clinics in India today".[29] The other indication of the growth is also the rise in membership of the Indian Society for Assisted Reproduction which was set up in 1997. Currently, the Society has more than 600 members.[30] There are also the infertility centres in smaller towns and rural areas, which work in co-ordination with referral ART centres located in tertiary healthcare institutes in cities. Parent IVF/ART setups have experienced gynaecologists and embryologists formally trained in this area and state-of-the-art facilities. Basic investigations and treatment are carried out by the infertility clinics while those requiring IVF and ICSI (Intra Cytoplasmic Sperm Injection) are referred to ART centres.[31]

In addition to a rise in Indian couples going in for artificial reproduction techniques, there is also a surge of aspiring mothers from other countries visiting here in search of donor eggs. Couples are coming from the UK, the USA, Russia, Canada and several other countries. This increase in medical tourism especially in the field of ARTs, in India can be attributed to the increasing commercialisation of ARTs. The facilities in India are less expensive; as some providers say, "it is like accessing first-world treatment at third-world prices." In this oppressive, pronatalist social

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26 Gary Potter, "Intra Urbem Extraque", The Wanderer, pp 3, May 18, 1989, http://www.ewtn.com/library/PROLENC/ENCYC055.HTM

27 Personal communication with Senior Scientist in NIRR.

28 ICMR, National Guidelines for Accreditation, Supervision and Regulation of ART Clinics in India, 2005.

29 ibid

30 Website, Indian Society for Assisted Reproduction, which was set up in 1997. http://www.isarindia.net/

31 Shardul Nautiyal – Mumbai, Build ART clinics and satellite centres in rural areas: Experts, Express Healthcare Management, December, 15-31, 2004.http://www.expresshealthcaremgmt.com/20041231/coverstory01.html.

scenario, made worse by commercialisation, the potential for exploitation of women is on the rise.

The industry- medical professionals, the pharmaceutical industry, are powerful and ruthless in their pursuit of profit. In the absence of State regulation and monitoring,[32] they also monopolise and manipulate research with the acquiescence of the medical community.[33] In the language of the ICMR Bulletin[34], "...it is estimated that for a population of one billion approximately 400,000 IVF cycles will need to be performed annually. This highlights the need for a large number of well equipped ART centres all over the country."

Conclusion

In this context, it becomes essential that in any discussion on assisted human reproduction, the implications of these technologies for women be thoroughly explored and evaluated. Concerns have been raised as they reflect and incorporate social arrangements and power relations. It is ironical that the debate on ARTs has very often neglected women. This is a significant omission, given that women not only carry the disproportionate share of the burden of infertility but also go through the ordeal of treatment.

The newness of these technologies and their constantly evolving nature are cause for concern given that often techniques are introduced without proper evaluation of their long-term effects and safety.[35] Women are often at the receiving end of these technologies either through experimental treatments or through inadequately tested procedures. They also become the providers of research material. However, the central problem is: "Nobody has asked whether IVF treatment is good for women. Wizards want us all to believe that infertility is practically unbearable but they do not want us to ask what becomes of the infertile woman who puts herself through repeated ordeals in a desperate quest for a pregnancy only to suffer a

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32 The only existing guidelines on ART being the "ICMR guidelines for Accreditation, Supervision and Regulation of ART ". However, this guideline as of now does not have any legal binding.

33 Sandhya Srinivasan provides an example: "Mumbai-based Sun Pharmaceutical Industries Limited bypassed the DCGI altogether and got private doctors to prescribe the anti-cancer drug Letrozole to more than 400 women for ovulation induction. They used the results to promote this drug through medical representatives for this unapproved usage. While there are debates about doctors' legal and ethical right to prescribe a drug off-label, off-label research done without following proper procedure is outright illegal 'Indian guinea pigs for sale: outsourcing clinical trials'. Sandhya Srinivasan. India Resource Center, Sept 8, 2004. www.indiaresource.org/issues/globalisation/2004/indianguineapigs.html.

34 ICMR Bulletin, Need and Feasibility of Providing Assisted Technologies for Infertility Management in Resource – Poor Settings, Volume 30, No. 6-7, June- July, 2000.

35 A.Oakely, "From Walking Wombs to Test- tube Babies", 1987, pp. 127-50.

miscarriage. Is she better or worse off than she was before the treatment"[36]? These are some of the key issues related to ARTs that deserve a critical review before these techniques are endorsed as liberating women by endowing them with choice. The fundamental aim of our research is therefore to bring them in the arena of public debate, thereby raising awareness about ARTs and their numerous implications and potential drawbacks.

36 Germaine Greer, "The Whole Woman", UK: Anchor, 2000

CHAPTER 2

Research Methodology

The main objective of the present research has been to unravel the social, medical and ethical implications of ARTs for women. This has been the special focus of our study, as we believe that an exploration of the implications that ARTs have on the lives of women would enable us to gain a more holistic understanding of the often-touted concepts of choice, empowerment and autonomy in the age of technology. The specific focus of the research was therefore:

- to look at the context in which women use ARTs, and the costs (physical, social, economic) incurred,
- to explore the provider's perspective on the "treatment" and its "users",
- to understand women's experiences and their perceptions of the "treatment", and
- to review the status of regulation, guidelines, policy at the national level and inherent ethical dilemmas.
- to understand the debate and engage with the concerns about ARTs across movements in India.

Research Methodology

A qualitative research was carried out in an attempt to understand the implications of these technologies on women's lives. Qualitative research methods were considered appropriate given the nature of the research. The focus was not on gathering quantifiable data from a large population but on documenting the perceptions and experiences both of the providers of these technologies and the women using them. The idea, hence, was not to provide generalising statements or trends but to cull out the various aspects of participants' experiences.

The research had two essential components: At the theoretical level, a systematic exploration of the field of ARTs is undertaken through

a) a review of existing literature; documents, articles, feminist writings, books and journals.

b) an analysis of advertisements, newspapers, websites, popular magazines, and the brochures of ART clinics[1]
c) a review of the ICMR National Guidelines for "Accreditation, Supervision & Regulation of ART Clinics in India, 2005".

At the empirical level, primarily qualitative research methods like systematic observation and in-depth interviews were undertaken with the providers of these technologies (gynaecologists, infertility specialists, embryologists) and with women undergoing these procedures of ARTs (Intra-Uterine Insemination, *In Vitro* Fertilisation, Intra Cytoplasmic Sperm Injection). This was helpful to understand the perceptions of providers and also the experiences and perceptions of women using these technologies. Checklists with open-ended questions were developed to facilitate the interviews.

A similar method was followed for the interviews with women's rights activists, health activists, disability rights activists and sexual rights activists to understand the debate and engage with the concerns about ARTs across movements. We also interviewed legal rights and human rights activists to understand their concerns regarding this issue.

Interactions with NIRR (Mumbai) and ICMR (Delhi) officials and surrogate agents were held. Visits to adoption centres, surrogate agents and public health institutions were also carried out as part of the research.

These personal interactions helped us gain a better understanding of the development and proliferation of ARTs. Given the fact there was not much secondary literature available in the Indian context, these interviews and discussions were immensely enriching and educative.

Study Area

The study areas chosen for the research were Mumbai, Delhi and Hyderabad. Delhi and Mumbai were chosen because these metros have some of the most prominent clinics and providers in the field of ARTs and cater to a population not only from within the city and the country but also from overseas. Hyderabad was chosen in order to understand the extent of infiltration of these technologies in a non-metropolitan city. The choice of the study area was based on the availability of human resources in a particular city, knowledge of the local language and familiarity with the city.

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1 The review of literature and documents is not mentioned in a separate section but is interspersed through the report.

Selection of participants

The study was carried out with providers of ARTs and women undergoing these procedures.

1. Providers of ARTs

A mapping of the different clinics in these cities was done through internet searches, from 'Ask Me' telephone services and advertisements in popular magazines. Providers were selected from a list of ART clinics available on the Internet.[2] Twenty-three providers were interviewed. Thirteen providers were from Delhi, six from Hyderabad and four from Mumbai.

2. Women using ARTs

Women undergoing these procedures were selected through advertisements published in magazines and women waiting to see providers in clinics in Delhi and Hyderabad. Twenty-five women were interviewed. Eighteen women were from Delhi and seven were from Hyderabad. Because of time constraints we could not interview women using these technologies from Mumbai.

3. Feminists, health activists and scientists

Twenty activists from various movements from Mumbai, Hyderabad, Kolkata and Delhi were interviewed. Three scientists each were interviewed from NIRR and ICMR.

Orientation

The research was coordinated by those members who had prior experience of working on issues related to women's health, reproductive technologies, assisted technologies and kinship. The main team was supported by other Sama staff, who worked for data collection, conducting interviews, and acquiring information from advertisements, websites, etc. Regular orientations were held for the team members to familiarise them with:

- the conceptual and theoretical concerns of the study, its rationale and objectives,
- concepts such as gender, motherhood and reproduction with respect to ARTs,

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2 http://www.pregnancymd.org/art-ivf-india.htm

- ethical considerations associated with ARTs; ethical issues involved in collecting data, approaching people and obtaining written or oral consent,
- reproductive physiology and anatomy

Meetings were held regularly with the research team to review the work, clarify doubts and follow the progress of the research.

Process of Gathering Data

1) The theoretical understanding was developed through an analysis of documents and literature available on the subject, in order to trace the various debates around ARTs. A literature review of the social and medical implications of ARTs was also undertaken.

A critical analysis of relevant policies, legislations and guidelines was undertaken to develop an understanding of the status of regulation and legislation that affect the ART "industry" and to identify issues needing public discussions and campaigns.

2) The process of gathering data both from providers and women was an intensive one. In-depth individual interviews were used to elicit perceptions and experiences related to ARTs. Checklists were prepared in consultation with health activists, social researchers, feminist scholars and practicing gynaecologists to help with the interviews. Checklists were initially developed in English and then translated into local languages to be used according to the geographical location.

In the case of providers, prior appointments were made so as to ensure that they could be approached at a time when they are willing to talk. When women approached us through advertisements, appointments at a convenient place and time were sought. Most women, however, were interviewed in the clinics before or after they had met the doctor. Follow-up interviews were conducted when the women were willing to discuss the issue further and provided us with their contact details.

3) Detailed personal interviews were held with activists. Questions were used but most of the times the activists were allowed to direct the discussion.

Ethical Considerations and Informed Consent

Informed consent, either oral or written, was obtained from both the providers and women interviewed in the course of the research. Information about the research (in English, Hindi and Telugu) was given in writing or communicated orally. It was emphasised that participation in the research was completely voluntary. The

participants were free to withdraw from the research at any point of time and could choose not to answer any question.

Confidentiality of women, providers and all those who were interviewed was maintained throughout the research period. Anonymity was ensured by maintaining codes in data entry. Care was taken to respect and protect the privacy and anonymity of the participants throughout the research. The names and identities of both women and providers were not revealed in any published document. Sama did not draw out contacts or any personal information of women from clinics, therefore preventing any breach of confidentiality between the clinics and the women. Thus, confidentiality of information was not only assured but also strictly respected and maintained.

An ethics committee was formed to look into the ethical issues concerning the research. The committee members were briefed about the rationale and specific objectives of the research and the methodology to be followed. Specific concerns raised and suggestions given by the committee were taken into account throughout the research.

Data Analysis

The study was qualitative and hence transcribed as a narrative. The participants were categorised on the basis of various criteria like geographic location, educational qualifications and occupational specialities (for providers) and age, educational qualifications, economic background etc, for women. From these categories, the research team culled out common threads based on experiences with the ARTs and their perspectives on it.

A review of medical literature was also undertaken. This was then compiled and analysed in order to highlight the health risks associated with ARTs. Social critiques of reproductive technologies, and discourses on motherhood, childlessness and reproduction were examined to gain an understanding of the inter-linkages between health, technology and society. A major component of the research has been an attempt to study the gendered social implications of ARTs.

Limitations

A number of limitations were encountered during the course of the study. First, as the providers were selected from a list of registered ART clinics from Delhi, Mumbai and Hyderabad, the study does not include information on clinics which are not in these lists or from small towns. Second, although prior appointments were sought with providers, interviews were often interrupted, and some were incomplete because the providers were unwilling to answer certain questions.

It was even more difficult to gain access to women undergoing ART procedures. This secrecy emerged from the stigma attached to infertility. Most women were interviewed in doctors' waiting rooms, and interviews were often abandoned midway as they were called in for their appointments. In this set-up, space and privacy were sometimes compromised. Also, the presence of the husband affected the women's interaction. A few of the women were also unwilling to share their contact details with us, which made follow-up interviews difficult.

Since the study group was small and the limitations many, we are wary of making any generalisations. However, despite these constraints, this study highlights various implications that the advancement of ARTs in India may have for women.

CHAPTER 3

Findings of the study

This chapter summarises the findings of the study in terms of the responses of providers and of the women undergoing procedures for ARTs. The findings from the research provide an opportunity to reinitiate the debate within the women's movement in India, regarding choice, autonomy, empowerment, as these techniques have the potential to propagate genetic determinism and eugenics in the guise of individual choice. The chapter is divided into nine sections that describe the findings thematically and are subdivided according to the providers' responses and the women's responses.

Section 1: Profile

This section describes the profiles of the providers and of the women undergoing the ART procedures. It is subdivided as: a. profile of the providers; b. profile of the women interviewed; c. profile of the women accessing these procedures (according to the providers).

1a. Profile of the providers[1]

Providers interviewed

In this study 23 providers–19 women and four men— were interviewed. They were interviewed in Mumbai, Delhi and Hyderabad.

Among the 23 providers, three were gynaecologists providing IUI only, two were embryologists working as part of an IVF team, two were gynaecologists working as part of the IVF team (but claimed to be infertility specialists), one was a medical graduate working as part of the IVF team and doing research on IVF. The remaining 15 doctors identified themselves as infertility specialists and head of the IVF team in their respective clinics. The embryologists interviewed were not medical doctors but one had a doctoral degree.

1 Providers have been addressed in this chapter as 'providers', participants, as well as by their code names. Women undergoing these procedures have been variously addressed as 'women', 'participants', and by their codes. Terms such as 'patients', 'treatment' etc. are used but stressed in quotes, because they do not reflect our position, as these technologies only assist reproduction, but do not 'treat' infertility.

Techniques offered and experience

Among these 23 providers, three had been using these procedures of IUI, IVF, and IVF-ICSI, for less than five years; seven of them for a period of eight to ten years; eight of them for a period of 11 to 15 years and five of them for more than 15 years.

Techniques not offered and reasons

Among the remaining 20 providers who were part of IVF teams and offered a range of techniques and procedures, one provider, P13/M, claimed that, "As a principle, I do not practise procedures which involve donor egg or sperm. I am totally against abortion and believe in pro-life philosophy. I am doing quite well without doing this and do not want to be like others. So you will find me quite different from the other doctors you have met."

One other provider, P2/D, claimed that, "Surrogacy is not practised because of legal and ethical complications for which we lose patients."

Whereas three out of the four providers in Mumbai claimed that they ran both commercial egg donor and surrogacy programmes in their centres, all the providers from Delhi claimed that the "patients" are asked to get their own egg donors/ surrogates. In the case of donor eggs they talked about an egg sharing programme in the centre. The providers from Hyderabad also claimed that the "patients" are asked to get their own donor/ surrogates. However, one provider claimed to have mediators who get egg donors, one claimed that they also get donors through personal contacts of staff.

Among the three gynaecologists who practiced only IUI, one claimed that she only performed IUI with the husband's sperm. As one provider put it, "In case of male infertility where donor sperm is needed, the male ego gets hurt as the husband feels that it is only his wife's child and not his. It is better in that case to go for adoption as a child is unrelated to both parents."

On the necessity and availability of specific training

Two providers felt that gynecologists should not practice IUI and it should be done only by infertility specialists. P9/D opined, "There are gynaecologists who are practicing IUI – this should not be done because they neither have the experience nor the expertise to practice it." Quite interestingly, she also said, "There is no specific training available in the country. I am working with Dr. __[2] for the last six years and have picked up from him."

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2 The names of the doctors mentioned have been left blank to maintain anonymity.

Four providers stated quite strongly that there was no need for formal training, as the experience of working with these procedures was more important. As P10/D put it, "Experience in monitoring the patient is important. The stamp is not that important."

P22/H - "There are no specific courses anywhere in the world. We have training through workshops and conferences. Essentially gynaecologists who are interested can provide services. Infertility is not recognised as a super speciality yet."

This might be read as a reflection of the insecurity of the doctors at two levels- at one level absence of access to exclusive use of these technologies by the "specialist"; at the other level, not having any formal bindings of certain specific qualification which then can derogate the status of the so called "specialist" to general gynaecologist.

1b. Profile of women interviewed

Twenty-five women who were either going through IUI, IVF or had been advised for any of these procedures were interviewed. All of them were married.

Age

Of the 25 women interviewed, the age of women who accessed procedures ranged from 22 years (youngest) to 46 years (oldest). Of these,14 women were between 30 to 40 years. One woman was above 40, while eight women were in their late 20s (between 27 to 29 years), and only two women were between 20 to 25 years.

Economic background

Thirteen women spoke about their economic background. Among these, five said that they belonged to middle class families. Two women stated that the monthly income of their household ranged from Rs. 10000-20000, four said that their monthly household income was between Rs. 35000 and 50000, and one woman said that her monthly household income was Rs. 1, 00,000. One woman identified herself as well-off.

Twelve women did not specify their income. However, two of them said they were from business families, two other women said their husbands worked abroad in Dubai and U.S respectively, one said that her husband was a government employee and they also owned land and property, one said that her husband works as a demonstrator in a cinema hall. The remaining six could not provide any details about their economic background.

Type of Family

Among the 25 women, 15 women mentioned their family types. Six women were from joint families, while the remaining nine were from nuclear families. One woman

said that she had to leave her joint family because of the constant pressure of becoming a mother. Ten women did not specify their family types.

Educational qualification

Fifteen women were graduates, four were postgraduates, two had completed their secondary education (10 grade/class), and four women did not specify their educational qualification.

Profession

Nineteen women identified themselves as housewives, two were teachers, two were engaged in business, one was a pathologist and one an engineer.

Religion

Twenty-four of the 25 women were Hindu and one woman was from the Muslim community.

History of prior conception

Nineteen of the 25 women had never conceived prior to the treatment. Two of the women had a child but were still undergoing treatment since one had an abnormal child and the other had a girl. Three had had early miscarriages, and one had undergone an abortion.

1c. Profile of women accessing these procedures (according to the providers)

Eighteen providers said that these procedures and treatment are accessed by people from all classes. Only five felt that it is only accessible to people of high and middle class. One of these five providers, P13/M felt that, " The poor are trying out options but the cost of the treatment bars them from using it."

The general idea among the providers that was categorically articulated by P2/D was that, "Requirement of baby is a phenomenon across class, so women and men even from the lower middle class come in for treatment. However, it depends on what kind of treatment they would need and whether they can afford that."

P8/D reiterated this idea and said, "If poor people go to the hospital when they are sick, why won't they come for infertility treatment when they are infertile. In a situation of infertility, people are ready to spend to have a child."

Providers also spoke about the ways in which they "help" couples from poorer economic background to access the procedures.

As P10/D put it, "We have a lot of people coming from lower class as we run a charitable OPD." Or as P20/H said, "There are many from the lower middle class. We tell them about all the procedures but encourage them according to affordability. If it is a lower or a lower middle class couple, we counsel them to go for donor sperm as it will be cheaper. If it is a couple from the rich class then they can afford ICSI."

The general understanding among the providers, which guided most of their reaction and response regarding class was that all "married couples" across classes, want a biological child of their own and they are ready to spend whatever is required, whether within their capacity or beyond. There is no acknowledgment of the fact that there can be women or couples who have chosen not to have child or have adopted children for that matter. The natural linear progression of marriage is childbirth at any cost and this is true for all classes of people "who are looking out for options".

Marital status

All the providers when speaking about women accessing treatment, referred only to married women. However, when asked specifically, three of them vehemently articulated that they do not provide services to single women though they have had requests.

As P18/H put it, "We don't provide services to divorcees or single women. They have to be a married couple."

What is also important is the perception among providers that in the words of P8/D, "Encouraging single women" would be "listening to one's head" and "not heart."

Two providers said that they have had requests from single women and they have done procedures for them. According to P15/M, "It is not like you need some trademark of marriage to use these procedures."

One provider said that it depends on the individual case as to which "single woman" would be given access - "A divorcee wanted to go through the procedure to have a child and I did it for her through donor sperm. However, an unmarried single woman wanted to bring donor sperm on her own which I refused."

The fact that for most providers the default setting is marriage, and their expressing reservation and even differentiating one kind of "single women" from another reflects the larger social framework which has its basis in the institution of

heterosexual marriage. None of the providers mentioned lesbian women/couples coming for these technologies. In fact, one provider quite categorically stated that even if "such" people do come in, they will be refused access to treatment outright.

Age

Nineteen providers commented on the age of women accessing treatment. A wide range emerged starting from 18 years to 55 years. While 15 of them said that the lower range of women who access treatment would be in their 20s, and the upper range would be women in their 40s, four felt that women start accessing the treatment only in their 30s, and the upper range goes up to women in their 50s. However, they expressed diverse views as to whether treatment should be provided to post-menopausal women. P15/M said, "We would treat women who are in their 50s in exceptional cases only." P4/D, in support of this view said, "There was a case in which a 55 year old lady came in with request of infertility treatment. Such requests should be discouraged taking into consideration both, best interest of the child and health implications for the mother."

Refuting this P11/D asserted, "If a woman is over 45 years but medically fit there is no reason as to why she cannot and should not use these procedures."

Some others like P8/D felt, "Post menopausal women also come for treatment. It is good that they can fulfil their dream of becoming mothers at this age."

P1/D felt that in her view menopausal women should not be taken in due to social reasons. "We do not take patients who are more than 45 years, and definitely not those who are above 50 years of age. I do not believe in making grandmothers, mothers. Some doctors see no harm with the age of the women exceeding 50, if they are medically fit and are able to sustain the pregnancy. However, such decisions are based on individual ethics of different doctors. Though a woman of 50 years might be able to give birth to a baby without complications, there are other important aspects, which have to be kept in mind. For example, if the couple is around 50 years of age, by the time the child is even 10 years, the parents would be around 60 years of age and it might be physically strenuous for them to bring up the child. In taking into consideration such issues, the aspect of compassion also becomes important. The huge age difference between the parents and the child (generation gap) might also be problematic for both of them in the future."

Thus, while young women coming in for treatment or consultation immediately after marriage were seen as "desperate" by the providers, those who came in too late were accused of "sleeping for too long" over their problem.

Religion

Except three providers, most of them did not specify the religion of women accessing treatment. Whereas one provider said that they have patients from all religious communities, the other two spoke of their perceptions regarding how religion plays a role in accessing treatment.

P13/M expressed his views that, "There is a resistance among the Muslim population who do not want to use these techniques. For them a new marriage becomes an easier option."

To the contrary, P20/H felt that, "In case of Muslim families, the couples come within two months of marriage as the men leave for the Gulf countries within two to three months. At such times, there is a lot of pressure on women to be pregnant and they seek treatment."

These statements reveal the providers' perception of a particular religious community and their construct of marriage and fertility within that religious community.

Section 2: Social context in which "assistance" is sought

This section discusses the social context in which "assistance" is sought. It is subdivided as follows:

a. providers' perspective: the social pressure to have a child; adoption is not an option
b. women's perceptions and experiences: the social pressure to have a "biological" child; motherhood as destiny; why adoption is not an option?; the process of "assistance"; the treatment pattern.

2a. Providers' perspectives on social context

Social pressure to have a child

"But first we must ask: what is a woman? 'Tota mulier in utero', says one, 'a woman is a womb'."

—Simone de Beauvoir[3]

The rhetorical discourse of "women as wombs" and primarily as reproductive machines, is very old and widely prevalent across societies. As Arthur Schopenhaur puts it, "Women exist, on the whole, solely for the propagation of species."[4] The

3 Beauvoir S de, The Second Sex, London, Pan Books, 1949.

4 Quoted in Gene Corea, The Mother Machine: Reproductive Technologies from Artificial Insemination to Artificial Wombs, New York: Harper and Row, 1985.

Indian scenario is merely an exaggerated manifestation of this thought process. This obsessive linkage of womanhood to marriage to fertility to motherhood, creates a considerable amount of social pressure, especially for women, to bear children. In such a context, the burden of infertility is great for a woman and often becomes the cause of social disgrace, ridicule and even grounds for divorce. Hence, the suffering caused by infertility is very real for women.

All 23 providers were agreed that couples – especially women — are under social pressure to have children. However, they made no attempt to question this situation. Instead, they proposed to deal with this social problem by providing a technological solution. They suggested that since women bear the disproportionate burden of infertility and childlessness, they would certainly be willing to subject themselves to all forms of medical and technological interventions in order to bear a child, regardless of the cost (physical, psychological, economic) that this may entail. Incidentally, it is this ideology and this social pressure that the providers exploit in subjecting women to various experimental technologies.

Some of these responses are reproduced verbatim in order to provide the essence of how the construction of women as "desperate" gets formulated and crafted:

"Teenagers with irregular periods come to me immediately after marriage as their mothers recommend them to go for it. At times, these things are hidden from their husbands and in-laws."

"The ridicule of infertility is faced by women across all classes. In case of upper class, it is more subtle. However, in lower strata of the society, the (infertile) woman is isolated and ostracised from all social functions and public spaces."

"Sometimes there is a lot of pressure on the woman to get pregnant in the first cycle itself. They go through a lot of psychological strain in such circumstances."

"When a patient comes to us, she would have already done everything else to have a child. They are desperate and are okay with everything to have a child."

"Women generally come with a lot of desperation due to the social ridicule they are subjected to."

"If you compare the need to have a child with the money involved, it is definitely worth it."

"These technologies provide solution to those couples who are desperate to have their own children."

Thus, there is no attempt on the part of the providers, to question this social pressure. Rather, it is reinforced by their perception of infertility, "as a major issue in our society", and by finding technological solutions to a social problem. By promoting these technologies, they believe that they are actually providing a "solution to those couples who are desperate to have their own children." It is interesting that although 19 of the 23 providers were women, there was no difference in the way they perceived the social context regarding infertility. However, there was more conscious recognition on the part of the women providers that this pressure of child-bearing unevenly falls on women because of the male dominated society.

Adoption is not the option

On the question of adoption as an option for infertile couples, only 15 of the 23 providers responded. Among these 15, eight providers were of the view that adoption is the last resort, considered only when all other treatment options fail. However, three other providers felt that, people who were open to adoption would not come in for the treatment at all and adoption cannot be imposed on couples as a viable option. Two other providers felt that, some people go in for adoption if they require donors. The remaining two providers said that they only recommend it to couples who, in their view, cannot afford expensive ART procedures. In the words of one provider, "Why should adoption be an option only for the infertile women?"

Adoption is thus seen as an option which is exercised only if nothing else works and even in their counselling and consultation, it is either advised when all procedures have been tried out, or when they feel that the couples cannot afford the cost of procedures. For the providers who are advocating these procedures it is not surprising that adoption does not feature in their interaction with couples but what is certainly surprising is that this last option is promoted as a priority only in cases where women cannot afford ARTs. Moreover, the onus is always on the couple's (woman's) desperation to have their own biological child and not consider adoption as an option.

It is the perpetuation of this social context that justifies and legitimises the introduction and proliferation of ARTs where every woman must become a mother after marriage and the child should be biologically connected to the couple. Although in certain cases, these technologies do not deliver a child that is biologically connected to both the parents, the fact that they do so secretly in a medical setting does not breach this model of motherhood at the level of the society. Thus, these technologies

far from subverting, in most cases, perpetuate and provide a helping hand in keeping the picture of a "happy married family" intact.

2b. Women's perceptions and experiences

Social pressure to have a "biological" child

As stated earlier, the social pressure to bear a child is immense, especially on women, however, the manifestation of this social pressure may vary. Usually it is internalised, where it takes the shape of guilt and shame on the part of the woman, but, however, sometimes it is overtly manifested in the behaviour of family, relatives, and neighbours, towards the infertile woman.

Nineteen of the women users commented on the social pressures to have one's own "biological" child. Sixteen of them said that there was no obvious demand from the family; rather they had been very supportive throughout the entire process. However, when the women started narrating their stories, they spoke about situations, contexts, aspirations and the normalcy of desiring and having one's own child. Their statements (reproduced again ad verbatim), however reveal the various ways- subtle and obvious-in which social pressure operated on them.

W1/D: "I have not faced any pressure from my family or my in-laws. However, relatives and friends always ask why we are not planning to have a child yet, given the fact that we have been married for the past four years. Everyone thinks that we are planning and taking protection. We cannot tell them that we have this problem and are going for infertility treatment."

W10/D – "My family has been quite supportive in the entire process. However, everyone wants that we have a baby. It's so late already."

W13/D – "There is no family pressure as such from anyone. But to feel the want to have a baby you do not really need to be pointed out and told. After you get married this is the automatic thought that crosses your mind. Even if no body says anything about it, everybody feels that we should have a child now that we are married for the last three years."

W14/D – "There is a constant pressure running through you even if you are not living with relatives. This creates an environment of trauma and you don't want really to communicate with anyone so that you don't have to face this question very often. They express their concern but they fail to understand that we would be best if we are left to ourselves and we would handle it in our own way."

W20/H – "My husband is very keen on having a child. I would have preferred not to have a child as the child will be much younger than us and it would be very difficult but he is very keen."

W12/D – "It is not like there is some kind of pressure on me to have a child that I can outwardly point to. But there are definitely subtle indications of it. We belong to a business family and the monthly allowance that you receive is higher for the *bahu* (daughter- in- law)_ who has kids. Now nobody says that the reason for this is her 'mother' status, but you needn't spell out everything in finer details to understand. It gets factored in one way or the other. She even gets more attention from the in-laws because they enjoy their *dada-dadi* (grandparents) status. It is not that they are rude to me or abuse me but rather there is a kind of pity which becomes all the more problematic. They are all highly educated and understand that the problem is with their son but at the end of the day nobody asks him about this. It is me who has to face the questions every now and then from relatives. It is also in your mind somewhere so even if people say something without meaning anything bad, you still feel bad about it. Like the other day, we were all chatting and a relative of ours said, "What will you understand about the problem of raising kids these days". I am sure she didn't mean anything specific and it was a very general comment but it hits you…this inherent pressure makes you feel traumatised, especially when someone else you know is having a child. After all, you are also a human being. How much can you take? How much will your husband also support you? He is also going through the same phase."

The statement above stands out because although she initially states that the "problem" was with her husband, it is she who feels the guilt and pressure and has to face the questions. Moreover, she was the one looking for her husband's support.

Though there was both a denial to accept this as pressure or to regard this pressure as natural, since childbirth was seen as a logical progression of marriage, most of the women expressed the need to clarify and justify their state of childlessness. This was because childlessness after marriage is something that is neither desired nor appreciated, and hence, the larger society asks for an explanation for the state that is not in conformity with the normal state of life. It is interesting that there was no marked difference in articulation of these sentiments with respect to education, economic background or family structures. Women living in nuclear families said that, "Even when you are living away from your relatives, their psychological presence in your life is immense."

Aside from the articulation of social pressure as external and from other people, it was also articulated in terms of one's own desire and necessity to have a biological child. This was accompanied with a concomitant feeling of guilt for not being able to perform the natural role of a mother after marriage. Central to this formulation is the language of "my wish" to have a child and the articulation of emptiness which only a child can fulfil.

As W11/D said, "There was no family pressure but everybody was praying that we have a child. It was specifically my wish, or rather our wish, to have a baby of our own."

W17/D – "There is no family pressure as such from anyone, but I myself feel the guilt for not being able to conceive even after six years of marriage. There is a feeling of emptiness (*khali khali lagna*) from within, which is difficult to explain to others, and I also feel depressed when I think about this."

Three of the 19 women said that they have faced "obvious" social pressure for not being able to conceive. W8/D said, "I was living in a joint family and I had to shift away with my husband due to the constant pressure of having children."

Another woman W19/H said, "He (husband) was abroad. There was a lot of tension in my mind about him marrying another woman, although he had assured me that he would not. Though people did not say it directly, I could sense that I was being treated differently. I was not invited for auspicious functions. I could sense them watching us."

These responses highlight the various shades of coercion in the lives of married women who do not have children, for whatever reason. Sometimes it is overtly manifested in the behaviour of family, relatives, and neighbours, but usually it is internalised, and takes the shape of guilt and shame. In this scenario, it is difficult to distinguish between an individual woman's conscious wish to have a child and the socialisation which makes married women feel incomplete unless they have given birth to a child. It also follows that motherhood is viewed as the woman's destiny. Hence, women often hold themselves responsible for their childlessness, even in the case of male factor infertility.

Motherhood as destiny

While most women did not articulate in definite terms their conceptualisation of motherhood, the notion was nevertheless interspersed with feelings of guilt and shame, and the women blamed themselves or their fate for not conceiving

"normally". The notion of motherhood as a unique experience was usually crafted around gestating a child for nine months.

W11/D: "It is not just about raising a kid. It is also about carrying a baby for nine months in your womb and then looking at that baby who resembles you and your loved one. This in itself is an experience you want to cherish and live through. I don't want to miss that beautiful experience. It is definitely not easy going through this process but at the end of it, you will experience the precious notion of what it means to be a mother. It is this thought that makes everything bearable."

W9/D - " *Tin tarah ka rin ho te hai sansar mei- guru ka rin, ma ka rin, pitri rin. Yehi aphsos rahe jaye ga ki koi mere se matritya ki bandhan me jore nehi rahenga.* (there are three kinds of debts in this world-debt of teacher, mother and father. I will regret forever that I have no one who is my own flesh and blood and nobody would be tied with me though bonds of maternity)."

This highlights a juxtapose that exists with respect to motherhood. It is at once, something precious and an integral part of a woman's reality, as well as a natural progression following marriage.

Eleven of the 25 women said that they had been trying to conceive ever since marriage.

As one woman W13/D said, "You do not really want to be pointed out and told. After you get married, this is the automatic thought that crosses your mind."

The notion of motherhood is so integrally related to the identity of a married woman that not being able to play the normal role of a mother, gives rise to feelings of shame and guilt.

As W9/D said, "But why can't I have a child? Maybe I have done something terrible in my life and now God is testing us. I thank God for everything else that he has given me in my life, but it is in this specific area that I am lagging behind. Maybe there is a right time for everything, and you are not supposed to fulfil that desire till the time comes. God knows!! I am beyond thinking. Still, I myself have started feeling guilty and feel that there must be some shortcomings in me only and that is why I am not conceiving."

These articulations are also indicative of the fact that women often perceive themselves to be responsible for childlessness, even when they are aware that the

problem is with their partners. This sort of reasoning emerges from the veneration of a woman's reproductive role, to the exclusion of all other roles that she may play in society. This feeling of guilt impinges dramatically on their self-esteem and affects their lives. Their self image is threatened as their "normal" feminine roles come under investigation and scrutiny.

The context in which assistance in reproduction is sought, is often articulated as two extremes of my wish to have a child, and the obvious external social pressure to conceive. However, a closer look at the issue reveals that the two extremes are not opposite ends of a straight line, but rather emerge from the same source—norms and values in the society that are imbibed consciously or unconsciously. The fact that this pressure often does not get recognised as something external or even as pressure itself is the way in which socialisation functions. The point here is not to look at one's own wish as false consciousness but just to highlight that it might be difficult to look at these articulations as fundamentally different from each other. The notion of guilt and shame for not conceiving and not being able to perform the much expected role even in cases where the partner is infertile, only reflects a social context, where there in no or very little space for women to think beyond the framework of "one's own child".

Why adoption is not an option

Nineteen women shared their thoughts on adoption as an alternative. Six women among these did not really consider it as an option. The reasons that they provided for this were varied. While two said that they have not thought about adoption because the, "Doctor never told us that we don't have hope of not conceiving. He said I would conceive through IVF."

One woman W9/D said, "Adoption for us is not an option at all. It might be feasible in cities like Delhi where people don't know each other are not bothered to find out who is who. Even if we go and adopt a child today, he would face social ridicule throughout his life. Everybody would say *"kis gandagi se uthake laya"* (which garbage dump have you picked up the child from)." Two women said that they did not think about adoption because "they wanted their own children" and "there was always a difference between your child and someone's child whom you bring up as your own." W23/H said," Because I conceived in the second cycle of IVF, I did not think about adoption."

Seven of them wanted to give "every possible option a try first". W4/ D articulated this by saying "We have not thought of adoption yet. We are not that old and we still have time to try. Why should we even think of adoption? No doctor has ever told us

that we will not be able to have our own child. At least we should try till the end and then only think of adoption."

Of six others who said that they had thought of adopting a child at some point, three said that though they themselves were open to the idea, they had faced resistance from their husbands and families. Some said that they did not consider adoption because the child would face social stigma and ostracism.

W4/D said, "Neither do we have the money nor the mental state to go for another IVF. So we are thinking we will go for adoption. Rather than wasting the money here on treatment, it makes sense to go for adoption and spend the money on the child."

W11 /D said, "When our second IVF cycle failed we thought we would register ourselves with an adoption agency because anyway it takes so much of time to complete the entire procedure" and "also carry on the treatment."

W12/D shared her dilemmas about adopting a child, "We have thought of adoption and are quite okay with it. But I don't want to adopt for selfish reasons. Here I will adopt because I am not having a kid of my own- so in my mind, there will always be this feeling that this child is not mine. We live in a joint family and have a huge business, so I don't want the child to grow up where everybody alienates him/her because he/she does not carry our gene pool. Moreover, the process to adopt is so difficult. How would you be sure that the baby does not have major diseases? I am not saying that there won't be people who would willingly adopt a mentally handicapped child and would like to raise the

Observations of some adoption agencies

Our interactions with a few adoption agencies in Delhi brought to light the following trends that the adoption agencies have observed among those coming in for adoption, "There has always been a higher demand for boys as compared to girls. The waiting list for couples wanting a boy could be as long as one to three years, while those wanting girls can find a match within six months to a year. Educated single women would generally choose to adopt a girl child. The people who generally opt for adoption are couples with infertility problems, or single women. Many couples come in after they have tried treatment for infertility and undergone some ART procedures or discontinued treatment due to financial constraints."

"Adoption is not a decision that couples come to with ease. It is generally opted for when they cannot have their own" children. Then too in the adopted child they look for traits/features that are similar to their families at least with respect to looks. The agency and the couple try to ensure that the child bears some resemblance to the couple and does not look out of place in the family."

"Irrespective of the general looks of the family, most couples want a fair complexioned child and if the child available for adoption is dark, a lot of couples decide against adopting. They are also looking for infants or children below two years of age. Sometimes people come as if they have come to buy vegetables in the market – they want big eyes, a sharp nose, fair skin etc. They have to understand that they are taking a baby and he/she cannot be rejected on such grounds."

child. But, I might not be in a position to do so – so how would I get assured that I am adopting a child who does not have thalassemia. These factors do come in. It might sound to you that I am a selfish person with selfish thoughts but we are all human and it is all about survival. At least we should have the satisfaction that we tried our best and till the last that we could. Otherwise, you are left with the feeling that we might have had a child if we have tried something out. I don't want to live with this guilt feeling in my mind for the rest of my life."

Most wanted to give birth to a biologically related child and hoped that this might be possible with ARTs – a hope that had been given to them by their doctors.

While for some, adoption was the last resort, for others, it was not an option at all. Even for those who had thought about it, they were still negotiating their beliefs and societal notions of what it means to have a child. Moreover, what was also recurrent was the hope rekindled by providers that they could have a child of their own if they went on trying, which also made them go through the process. These ideas about adoption may be skewed from the point of view that the sample only comprised of women who were either going through the process of assistance or had decided to do so. Given that, what was also important was how the issue of adoption gets closely linked to issues of fertility and infertility. If someone was adopting a child, then the primary assumption was that they were not capable of having their own.

The concern with "blood", "genetic make" and the "legitimacy" of the adopted child were also major stumbling blocks for adoption. There was also lack of information on the process of adoption. Inherent in all these was the guilt for not trying hard enough to have a child. This guilt was further fuelled and rekindled when hope was given by providers that they were capable of achieving the ultimate goal of bearing children if they tried persistently.

Process of "assistance"

Twenty-one women spoke of their first encounter with providers and thereby ARTs. Of them, nine sought some kind of treatment within six months to one year from the time that they started trying to conceive; four women within one to three years; and seven after three years. Five said that they did not remember at what stage they first consulted a doctor.

At the initial stage of treatment, 11 women went to gynaecologists, six went to an infertility specialists, two to Ayurvedic doctors, one to both a general physician and a *"guruji"* and one woman to a general physician. Four women either could not remember or did not specify whom they went to.

Nine women had their first contact with the providers was within the period of one year, which highlights the fact that ambiguous definitions of infertility are internalised by the women, and are used as yardsticks to decide on when to seek treatment. Thus, the medical definition of infertility does not remain restricted to the medical domain of providers and researchers, but is also imbibed by the women, and influences their understanding of it as well.

Treatment pattern

Among the 25 women interviewed, five had visited only one provider and were continuing treatment with them, 12 women had already visited two to three providers, two went to six providers and four women visited more than six providers. Two women did not say anything about the number of providers visited in the course of their treatment.

As, W9/D said, "I don't even remember the innumerable doctors we visited. Initially, we went to our general physician. In all these years we have visited gynaecologists, urologists and many others. But nothing has happened. In the last so many years God only knows how many doctors we have visited. We have been doing whatever we have been asked to do. We don't even know what the problem is. We went to Dr. --[5] and he advised us to go for IVF. We had done two IVF cycles but both of them failed. Then we went to some one called Dr. --. She suggested IUI. After this, we left the treatment for almost two years. Then a relative of ours in Delhi (my husband's sister) advised us to come for treatment here and so we started treatment with the present doctor."

W10/D – "In Haryana, we have been to numerous doctors. We have gone through all kinds of diagnostic tests as and when told by the doctor but there was no problem that was diagnosed. Then we have also gone to Dr. -- in Patiala. She advised us to go for IUI. Then a relative of ours in Delhi told us to visit Dr. -- in Greater Kailash. She also did all kinds of diagnostic tests and said tube is okay, egg is also okay and my husband's semen is fine too. But we still did not conceive. Then we came to know about the present doctor."

W1/D – "After trying out three doctors in Delhi, we even went to a doctor in Ireland. He advised laparoscopy. Both the tubes were fine. My husband also underwent a semen analysis test and were advised to go for IVF. Now we are back in India and consulting another doctor."

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5 The names of the doctors mentioned have been left blank to maintain anonymity.

W6/D – "I have come all the way from Kanpur. We have a ten year old son but he is not a normal child. Initially, we visited a few doctors in Kanpur and then our relatives in Delhi told us about this doctor. We have been with her for seven-eight months, but no success yet. It is difficult to come all the way from Kanpur, and to leave our son with relatives is even more difficult."

The reason for this trajectory of treatment, where most women visited more than one doctor, is that often "nothing happened". It represents the treatment seeking women and couples as a mobile population travelling from one city to the other in search of a "good" doctor, thus making the ART clinics the new sites of pilgrimage. This phenomenon of "doctor shopping", also occurs because the doctors do not devote enough time to each patient, give information in a piecemeal fashion, and sometimes lack sensitivity in dealing with the issues of these women. However, these are secondary reasons. The fundamental cause of "doctor shopping" is that in advertising about the ARTs, their success rate is over emphasised. The reasons for changing doctors is sometimes guided by the fact that a relative or a friend had a successful experience with a particular doctor or that the couple in their interaction with other couples, had heard about the goodwill of a different doctor. This raises the expectations of the patients, which are often remains unmet in practice. However, this does not lead to questioning the technologies but often results in the women questioning their own fate and sometimes the doctor's competence. But the inherent belief in the capability of medical interventions to change their lives is maintained.

Section 3: Infertility

This section deals with the issues and perceptions of infertility. It is subdivided as follows:

a. providers on infertility: trend of infertility; reasons for infertility
b. diagnosis for not conceiving as understood and communicated by the women

3a. Providers on infertility

Trend of infertility

Most providers stated that they believed that treatment for infertility was on the rise because infertility as a "disease" had been increasing, as had people's awareness about available treatments.

P19/H said; "Earlier infertility was about 20 per cent, now it is approximately 40 per cent. However, there is also an increase in awareness. Almost 90 per cent of the men with problems seek treatment. Earlier, there was a lot of hesitation on their part to do this."

Six of them were of the opinion that, infertility as a problem has not increased but the couples seeking treatment have definitely gone up over the years.

As P11/D quite categorically said, "There is a general feeling that infertility is on the rise. However, the exact validity of these kinds of opinions is difficult to establish. Firstly, no clear statistics are available on infertility for comparison. Secondly, infertility being a sensitive issue, people do not generally come out in the open with it. Thirdly, treatment for infertility was not widely accessible to people earlier. Increase in infertility might be reported to be on the rise because of the number of people coming in for treatment. Also, more and more people are now open about male infertility, which was not the case a few years back. Increased awareness and information regarding infertility, and more treatment options available to those seeking treatment are a few of the factors accounting for an increased number of infertility cases being reported."

P8/D also articulate similar concern in different language, "Earlier there were at least 25 per cent people who would come for treatment after adopting a child. There was almost no treatment for infertility – the only option was to go for a second marriage or adopt a child. However, now with growing awareness among the general population and among the doctors themselves people are coming at an early age."

However, there is an absence of epidemiological data on the increased prevalence of infertility and also no statistical compilation indicating an increased availability of treatment.

Reasons for infertility

Nineteen providers felt that the aim should not be to know the reasons behind infertility, but merely to assist in having a baby. Regarding the reasons for infertility, all 23 providers classified infertility as male factor, female factor, both and unexplained infertility. The various possible medical reasons given by them for male factor infertility were: subnormal sperm count and function; low sperm mobility; low sperm survival; poor sperm morphology; impotency, and premature ejaculation. For female factor infertility, some causes that were listed were: tubal block; moderate or severe endometriosis; poor cervical mucus; untreated sexually transmitted infections; genital tuberculosis; untreated Chlamydia; hormonal disorders causing ovulation problems, and premature menopause.

The providers also listed lifestyle reasons and environmental reasons leading to infertility: "Consumption of poor quality alcohol, smoking of bidi among men from lower class leading to low sperm count"; "increase in prevalence of pelvic

inflammatory disease (PID) and low sperm count due to environmental causes" and "promiscuity leading to STIs" and "work-related stress" were some reasons given.

Five providers also attributed infertility among women to their "marrying late", "being career oriented", "delaying pregnancy" and "postponing child-birth till 30s." This sort of special mention given to women and their decisions, emerges from and reflects the idea that women's role, till date, is primarily crafted around her reproductive potential. The assumption throughout is that infertile women are not fulfilling their "natural" role of motherhood.

This idea of a "success oriented approach to infertility" is articulated in the website of a reputed clinic in Mumbai.[6] *Though the provider was not a part of our sample, extracts from the website have been reproduced here to provide an idea of the way in which infertility is perceived.*

"This new approach to infertility is very different from the traditional medical approach, so it needs to be described in detail. Many infertile couples want to know - "What is the diagnosis, doctor? Why am I not getting pregnant?" Or "Why did the IVF cycle not work?" However, we feel this is the wrong question - and if you ask the wrong question, you get the wrong answer!

Rather than focusing on what your problem is, you should focus on the solution - which is a baby! This means that the question you should be asking is "What can we do to maximise our chances of getting pregnant?"

Instead of spending time, money and energy on diagnostic testing, it makes more sense to select treatment options which maximise the chances of getting pregnant. You should concentrate on treatment paths and action plans - the next step forward, rather than worry about diagnostic labels.

Fortunately, today with IVF technology, we are better at solving problems for infertile couples rather than diagnosing them. This often means that while we may not be able to explain why embryos did not successfully implant after IVF, the chances of success by repeating the treatment cycle remain excellent."

3b. Diagnosis for not conceiving as understood and communicated by the women

Among the 25 women interviewed, three stated that the problem had been identified as male factor infertility (low sperm count and motility). Of these three, one was undergoing treatment because her husband "could not have sex as he was impotent."

Ten women stated that they were told that it was female factor infertility. Three women were told that a combination of factors was responsible. Of the 13 women with female factor and combined factors infertility, three either had blocked tubes or some other problem with their tubes; one had irregular menstruation; and two had cysts in the ovary. One was diagnosed as having both low prolactin levels and endometriotic cysts. Two had Poly Cystic Ovarian Disorder (PCOD). Four women were diagnosed with having a problem with egg formation of whom one was

6 http://www.drmalpani.com/aboutus.htm

diagnosed with "non ovulation due to prolonged use of contraceptive pills." For one woman, age was a factor for seeking treatment.

Seven women had been informed that the diagnosis was "unexplained infertility". Two women did not have any idea of the diagnosis. Of those with "unexplained" infertility, one said she was first told that her husband had a low sperm count, but later that it was normal; their "case" was one of "unexplained infertility". Another reported that she was initially given medicine for "good" quality egg formation, but later told that "everything is normal".

The women voiced their dejection and frustration in many ways. W9/D: "We have been doing whatever we have been asked to do. We were never told what the problem is. Anyway, it is for the doctor to know."

Another woman, W12/D reflected that, "The doctor found out that my prolactin level was 29 to 30. They attributed this as the reason for my not becoming pregnant. But I know women whose prolactin was as high as 50, and who have given birth to babies. When the doctors have to give a reason, they just say anything. In 2006, I had to go for a laparoscopy, and they found out that I had a minute endometriotic cyst. But, they are saying that that can't be the reason for not conceiving. So basically, they also don't know what the reason might be. They are just hunting in the dark to find something."

Section 4: Informed consent and the nature of information and counselling

This section deals with informed consent and the nature of information and counselling provided with ART procedures. It is subdivided as follows:

a. Informed consent:
   a1. providers on informed consent;
   a2. women on informed consent

b. The nature of information and counselling:
   b1. the providers on information and counselling provided;
   b2. women on information and counselling provided

c. Information regarding egg retrieval and implantation

4a. Informed consent

4a1. Providers on informed consent

Informed consent requires full disclosure and fair representation of all the potential medical, social and emotional outcomes and risks that may follow the use of ARTs.[7] Only nine among the 23 providers mentioned the use of an informed consent form and only two agreed to share their forms with the interviewers. Three said that their informed consent forms were photocopies of the ICMR guidelines and four said that they had different informed consent forms for different procedures. One provider said, "Both the partners are asked to sign the informed consent forms at the time of registration for the IVF cycle." Another said, "The informed consent forms are both in English and the local language." Two said, "All side effects are mentioned clearly" and "We explain everything to them and sometimes they sign the form without even reading it." Three providers stated that informed consent forms are basically disclaimers to ensure that the clinic will not be held responsible in case of any complications or problems.

4a2. Women on informed consent

So "thoroughly briefed" was Lesley Brown[8] that until just before the birth of Louise, she assumed hundreds of test tube babies had already been born. Describing the first meeting she and her husband John had with Patrick Steptoe, she wrote: "I don't remember Mr. Steptoe saying his method of producing babies had ever worked, and I certainly didn't ask. I just imagined that hundreds of children had already been born through being conceived outside their mothers' wombs. Having a baby was all that mattered. It didn't seem strange that I had never read about anyone who had had a child in that way before. I could understand their mothers wanting to keep quiet afterwards about how their children had been started off. It just didn't occur to me that it would almost be a miracle if it worked with me."

—Gena Corea[9]

The information obtained from the women participants on the issue of informed consent was also very sketchy. Seventeen women spoke about the informed consent forms. Six said that they had never signed any informed consent form — or any written material for that matter — while going for IUI. Six said that they had signed informed consent forms or some other kind of written material while going for IVF. One woman said that she did not sign any informed consent form even for IVF.

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7 Bioethics for clinicians: 26. Assisted reproductive technologies, Laura Shanner and Jeffery Nisker, CMAJ. May 29, 2001; 164911)

8 Mother of the first 'test tube' baby, Louise Brown.

9 Gena Corea, The Mother Machine: Reproductive Technologies from Artificial Insemination to Artificial Wombs, New York:Harper and Row, Pp 167.

Another said that though she did not sign any informed consent form during IUI, she signed a consent form while registering for IVF. In sum, only seven of the 25 women interviewed reported signing an informed consent form which they read – or which was read out to them.

Regarding the content of the informed consent forms, four said that they did not have any idea as their husbands signed it on their behalf. Three were of the view that informed consent forms are mere disclaimers protecting doctors in case of complications that may result from these procedures. Only one woman, said, "Yes, we signed an informed consent form. I read the form—it had details of the side effects and the success rates." Another woman said, "We signed the informed consent form which was in English. As we don't understand English, the doctor narrated the contents to us in Telugu. The doctor told us that there may be some side effects and also that the success rate was low."

W9/D – "For the IVF cycles we had to sign consent form. My husband signed the form and I won't be able to tell what the content is."

W6/D – "During the registration of the IVF process we were given an information booklet and registration form. We also signed an informed consent form."

It appears that informed consent was rarely obtained from women before undergoing procedures of ARTs. Even when these forms were signed, it was usually by the husbands, and very rarely by both partners. All the necessary information needed to formulate a truly informed choice, was not usually disclosed. The language in which the informed consent forms was drafted also made it difficult for everyone to understand them.

4b. Nature of information and counselling

Whenever people come for any medical treatment, it is good medical practice to give them complete information so that they can make a truly informed choice. This must include the treatment's side effects and complications, its efficacy, and alternative treatment. Counselling is equally important, especially because of the emotional stress associated with infertility. It is also important to prepare couples for the possibility of repeated failures to conceive, and the risk of unpleasant side-effects and dangerous complications.

4b1. Providers on information and counselling

Only 12 of 23 providers responded to a query on the type of information and counselling given to women undergoing these procedures. The information was

mostly about a few side effects (mainly excluding the more serious and significant ones like ovarian twisting, for example), with some details of the procedures, figures on success rates, and costs. Counselling seems to have been done only for couples with "special" cases like where "both the husband and wife have thalassaemia" or when donor sperms or eggs would be used.

This reinforces one's impression that the information provided is primarily piecemeal and inadequate. In fact, only one provider claimed to give complete details along all the criteria mentioned above. Doctors seem to use the hierarchical patient-doctor relationship to control women's access to knowledge. They believe that they are not bound to impart comprehensive information. In this scenario, it is difficult for women either to have a complete picture of the process they are embarking upon or to be part of the decision-making process.

4b2. Women on information and counselling

Ten of the 25 women interviewed said they did not know much about the treatment as the doctor was always was too busy or they were hesitant to ask. Eight said they had some information on the procedures' and success rates only. One woman said that she was categorically told by the provider that there would be no side effects or complications.

W6/ D – "No information was given. "She (doctor) is so busy that there is hardly any time for her to talk to us or explain or listen to our problem." W7/ D – "No information was provided. The doctor said she would tell us what to do as and when required."

W9/ D – "They don't give you the full information at a time. They say this process did not work for you so now go for something else."

W10/D – "I am going for an IUI today. She has prescribed me treatment but I have not been able to talk to her regarding anything. She is busy and you also don't know the nature of the new doctor. She might get angry, so I did not ask anything. The problem with asking the doctor is also that they are so busy that they very often do not explain you clearly whatever you want to know. Moreover, they often explain in English so you cannot comprehend half of it. What to do, we studied in a Hindi medium school that is common in Haryana."

W25/H - "Last week the doctor screened a film. It was quite informative as it gave the technical details of IVF and other procedures."

Though some of the women expressed their dissatisfaction with the lack of information, others felt that the doctor might have told them — if they asked. They hesitated to ask the doctor, for fear of offending him/her. The duration of the treatment was an important variable that affected the amount of information that the women had. That is, women who had been undergoing treatment for a long time (five years or more), had more information, and were also more articulate in their negotiations with the providers.

4c. Information regarding egg retrieval and implantation

Among the providers interviewed, six commented on egg retrieval, stating that the number of eggs retrieved depends on individual women. The range varied from five to 16 eggs. In one case, a provider claimed to have retrieved 35 eggs. Regarding the maximum number of embryos implanted in one IVF cycle, eight providers responded saying that it varies between two to five, with three being the most common.

Of the eight women who underwent either IVF or IVF-ICSI procedure, three did not have any information regarding number of eggs retrieved, eggs implanted and what happened to the rest of the eggs. Their bewilderment on the lack of information was aptly reflected when W9/D said, "We don't have any idea of how many eggs were retrieved or how many were implanted. Only the doctor knows that."

The remaining five women had varied kind of information on these. W4/D knew that some embryos were cryopreserved but had no idea of the number of eggs retrieved or implanted. While W3/D knew that only three out of the five eggs retrieved were implanted, she professed that neither had she asked about the eggs that weren't implanted, nor had the doctor voluntarily provided any information as to what happened to them. Only three women had clear information on the number of eggs retrieved, implanted and the status of the leftover embryos. However, W11/D who was one of them, mentioned that in her first IVF cycle she did not have the full information, "I didn't know what happened to the other eggs in the first cycle. We never actually asked about it."

There are many issues raised by large numbers of egg retrieval and implantation. Retrieving large number of eggs (as in the case of retrieval of 35 eggs), requires hyper stimulating the ovaries through intake of hormonal drugs, which often entails serious medical complications for women. Moreover, the procedure in itself is highly invasive, and may result in serious damage/harm to the woman undergoing it. Often more than two embryos are implanted to improve chances of pregnancy. However, this may result in multiple pregnancies. In this case, the woman had to undergo foetal reduction which again poses many health risks. Another pertinenet question raised is

what happens to spare embryos? Are they sold or donated for research, or simply discarded? This process of retrieving large number of eggs also poses many ethical questions in the context where the spare embryos were supplied by IVF clinics for stem cell research.

Doctors give women mere directives, which misguide them and make women go through the process over and over again. There was somehow also a feeling among the women that it was their own responsibility to ask and know about such information and not the doctor's duty to provide it to them voluntarily. Thus, in most cases they did not blame their doctor for not giving the information but felt that it was their lack of experience or knowledge, which made them refrain from asking questions. However, this practice of providing selective information without considering the consequences of this for women, calls into question the ethics of medical practices.

Section 5: Side effects and complications

This section deals with the side effects and complications of the drugs and procedures. It is classified as:

a. Providers on side effects and complications of procedures
b. Women on side effects of drugs and complications of procedures

No. of providers	Health Risks
14	OHSS
10	Multiple Pregnancy
4	Ovarian Cancer
3	Ectopic Pregnancy
3	Obesity/bloatedness
2	Miscarriage
2	Allergies
1	Edema
3	Risk of anaesthesia (donor egg retrieval)

5a. Providers on side effects of drugs and complication of procedures

Nineteen of the 23 providers spoke about the side effects and complications of the drugs and procedures. In general, they said that there were no major health risks. Some did name some risks, when they were probed, but tried to minimise them by presenting it in the form of a risk-benefit analysis.

P11/D said, "If the benefits outweigh the risks then it is worth taking the risks. There are no major side effects of the drugs used for the infertility treatment. Side effects are nothing compared to the lifelong problem a woman faces due to infertility."

P21/H said, "Drugs are used to stimulate the process, but side effects vary from person to person. For example, if I have aspirin it may not react, but for some other person it might."

P1/D pointed out, "High possibility of miscarriages takes place in cases where women do not take proper care of themselves after conception."

P8/D - "There are no side effects of these techniques; it is basically assisting the natural process." However, on probing, he said, "There are chances of multiple births, twins mainly, but we don't consider this as an adverse effect. There is a myth about the hormones used during an IVF cycle. One needs to know that these hormones are natural hormones which are produced by the body naturally. So they have no long term effects once they get metabolised by the body."

It was only after probing that they mentioned risks such as: ovarian hyperstimulation syndrome, a life-threatening complication of the drugs used to stimulate production of eggs; multiple pregnancy as one of the outcomes of a stimulated IUI cycle or IVF (they did not feel this to be an adverse effect); obesity, allergic drug reaction, miscarriage, edema, ectopic pregnancy, ovarian cancer, and risks such as perforation associated with the process of egg retrieval.

The providers attempt to place the burden of risks and complications of the procedures on the women, who "willingly" undergo the procedure to have a child. In an attempt to "justify" or "defend" potentially risky techniques, these side effects are portrayed as minor, negligible in comparison to the necessity and "desirability" of having a child.

5b. Women on side effects of drugs and complication of procedure

Of the total 25, 15 women could not remember either the names of the drugs and injections that they had taken or the purpose of taking medication during the course of the ART procedure. While one woman mentioned taking " Some medicines for egg formation", and another of "hormonal drugs", the other eight women merely specified the name of the drugs. Of them, two mentioned taking Letrozol along with Profasi and one among them was also taking Fermotid, Uteron and Puregon. The other drugs that were administered to the remaining six women were Buecedin,

Metformin, Brufecin/Bruclin, Lupron, Gonal F, Progynon, Depo Provera and Naturogest.

Only 16 women among 25 responded to this query. Three women categorically stated that they "did not experience any discomfort" from the procedures, or "there were no side effects of the drugs". Thirteen women reported facing some side effects, of which three were not sure whether they were related to the treatment.

As W6/D said, "I have not felt medical complications in the procedure. The only thing is that I am getting fat and there is heaviness in the chest."

W25/H said, "I did not have any major side effects, except a little constipation."

W22/H - "I did not have any side effect, but a few days back, I had bubbles in my stomach."

The remaining 10 women mentioned what were clearly side effects of the drugs. Primary among these were weight gain, fatigue, increased micturation, mood swings, giddiness, skin rashes, fevers, hot flashes and a feeling of bloatedness. As W2/D recollected, " The medicine Metformin reacted. I had a bloated stomach and pain in the abdomen."

According to W17/D, "There are definitely side effects of the various medicines that I have been taking. I have gained weight; there is constant feeling of giddiness also. Intake of these medicines sometimes also results in sudden rise in body temperature, and I feel very hot."

W10/D expressed, "I have been taking these drugs for so long that now I feel my body is not like it used to be anymore. *Urine mein garmi si rahena to routine ban gaya hain* (it is routine now to experience a sensation of heat while passing urine). I am also putting on weight on a regular basis."

W13/D – "My periods are painful with nausea, loose motion and sometimes its unbearable. I generally lead a healthy life with all the support of good food, good hygiene and may be that's the reason the side effects of the drugs are not manifesting so badly. However, my skin was really good but now its full of pimples. I feel that's because of the hormones."

W14/D – "These drugs definitely have side effects. I have put on quite an amount of weight and I have such terrible mood swings these days, which I never had earlier."

Two women described the pain of the laparoscopy... "*uo durbin laga ke* (the way the laparoscope lens was inserted). That was painful..."

However, it seemed that most women had accepted the pain and side effects as something minor and integral to the treatment. They had been told as much by the providers, who also posed this in the form of a risk-benefit analysis. All this had to be endured in order to get the desired child.

Section 6: Success of the techniques

This section is on the success rates of the techniques. It is subdivided as:

a. The "success" of the techniques as quoted by the providers: success rate of IUI and IVF; success rate of IUI as quoted by the providers; success rate of IVF
b. The "success" of the techniques as experienced by the women

6a. The "success" of the techniques as quoted by providers

It is difficult to have a comprehensive idea of success rate of these technologies in the Indian context, given the absence of a central registry for ART clinics and the use of standardised definitions of success rates. Often, the implantation rate or the chemical pregnancy rate[10] was quoted as the success rate, rather than the live births rate or the "take home baby" rate – the number of pregnancies that result in the birth of a child that survives. Providers seem to be manipulating these various definitions to their own advantage, using them to promote ARTs in general and their provision of them in particular. Their argument for quoting the implantation rate rather than the live births rate was that women were referred to them for infertility treatment, they went back to their gynaecologists once they conceived, and it was not possible to keep track of the take home baby rate.

It is only on probing that the take home baby rate was quoted. It is only two providers among 23 who directly quoted the success rate as the take home baby rate.

Success rate of IUI and IVF

The doctors also provided reasons justifying higher success rates in their clinics as compared to others. As doctor P5/D said, "The success rate of IUI is much higher in my clinic due to the medium used (Medicult, which is used in IVF) and newer medicines GNRH (new purified gonadotrophin). It also depends on patient selection – women within a particular age range, or men having at least a certain amount of semen count."

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10 Pregnancies confirmed by blood and urine tests but in which the embryo may not be formed or develop beyond the earliest stage

As P8/D said, "Success rate of IVF can be 60 per cent if the reason for going for IVF is only male factor infertility. Moreover, if women are young, success rate can go up to 70 per cent."

According to this doctor the take home baby rate was not quoted because in most of the referred cases, following conception and pregnancy, the women were sent back to their gynaecologists and hence it was not possible to keep track of the take home baby rate.

The significant difference between the implantation rate and success rate was attributed to the large number of miscarriages that happen when, in the words of P1/D, "Women return to their respective gynaecologists for delivery" and "Don't take proper care of themselves once the implantation process is over."

Success rate of IUI as quoted by providers

Ten providers cited the implantation rate of IUI in their clinics, and these ranged from 15 per cent to 50 per cent. On further probing however, some of them also offered the take home baby rate. Six said it was "almost" the same as the implantation rate. One said the take home baby rate was between eight per cent and 12 per cent. One did not provide the take home baby rate at all.

Success rate of IVF

Twenty-one providers commented on the success rate of IVF. Among these, 17 gave the implantation rate as the success rate. This also varied widely and ranged between 10 per cent to 50 per cent. Only three directly quoted the take home baby rate as success rate, and it ranged between 20 per cent to 30 per cent. One of the 21 providers did not mention any specific success rate of IVF, but said that 90 per cent women get pregnant in three cycles.

Of the two providers who quoted the success rate of IVF with cryopreserved embryos, one claimed it to be seven per cent and the other as 35 per cent.

One provider, P14/M claimed the success rate (implantation rate) of IVF-ICSI to be 40 per cent but on probing said it varied between 20 to 30 per cent. Of the two providers who quoted the take home baby rate only, there was a wide gap from 25 per cent in one case to 45 per cent in another.

The quoting of implantation rate as the success rate indicates an attempt to mask the actual success rate i.e. live birth per IUI/IVF cycle. The way in which these various terminologies like implantation rate, chemical pregnancy rate gets synonymous with live birth rate brings out new meanings of "what it means to be pregnant".

Women considering assisted reproduction should be given a realistic picture of their chances. Selectively quoting success rates presents a rosier picture of ARTs than may actually be the case. It also betrays the faith that women put in their health care providers.

6b. Success of the techniques as experienced by women

Regarding the success of the techniques, women responded with the understanding that it varied and depended on individual cases.

W1/ D - "Every doctor has his / her own success rate and it depends on the individual patient."

W5/D - "I don't know if they have said anything about success rate (of IUI). My husband might know and remember. What is there even if the doctor says that the success rate is this much? Ultimately whether it will be a success or not depends on individual bodily constitution. Some people conceive after one IUI and some don't even after several cycles of IUIs and IVFs."

W13/D - "The doctor said it has 10 to 14 per cent success rate. But you never think that it would fail in your case."

The most striking feature, however, was the number of ART cycles that the women were willing to endure. Fourteen of the 25 women interviewed went through IUI. Five women conceived, one in the first cycle, one in the second cycle, two in their third cycle and one in the fifth cycle. Three women reported having undergone two to three cycles, four women had undergone four to six cycles. One woman had gone through eight cycles and not one of these had resulted even in an implantation of an embryo.

Four of the remaining 11 women had undergone IVF. Three had become pregnant. Three of the 25 women went through all three procedures - IUI, IVF, and IVF-ICSI. Only one of these three women became pregnant, in the second IVF-ICSI cycle. Before she became pregnant, she underwent five IUIs, one IVF and one IVF-ICSI. One woman underwent three IUIs followed by one IVF. One woman had two IVFs followed by five IUIs, all of which failed.

One reason they may have persisted is their doctors' individualising the success rate of the techniques:

"What is there even if the doctor says that the success rate is this much? Ultimately whether it will be a success or not depends on individual bodily constitution. Some

people conceive after one IUI and some don't even after several cycles of IUIs and IVFs."

It is frightening that so many women, even in our small study sample, repeatedly put themselves through uncomfortable procedures in order to get pregnant and bear a child. This is how couples enter the slippery slope of reproductive technology. It is almost impossible for them to first decide when enough will be enough. Added to the guilt of not being able to conceive is the guilt of not having tried hard enough.

Section 7: Costs involved

This section is based on the costs incurred during various ART procedures. It is subdivided as follows:

a. Providers' views on the cost involved
b. Women's views on the cost involved

7a. Providers' views on the costs involved

Eleven providers quoted the cost of IUI. While some of them quoted the cost of the procedures, others spoke about the cost of the IUI package. The cost of the procedure ranged from Rs.1000-2500. The package comprised of consultation, follicle monitoring, and two cycles of IUI and ranged from Rs. 2000-10000.

The cost of the IVF procedure as articulated by 18 providers ranged from Rs. 5000 to Rs. 1 lakh. The providers who gave the break up of the procedure and drugs, the cost of the procedure ranged from Rs. 20000 to Rs. 55000. The cost of the procedure varied widely from provider to provider depending on their power to cash in on people's vulnerabilities, although they claimed that cost of drugs was the primary cost in IVF.

However, in addition to the arbitrary way in which the cost of the procedure is set, it is also important to look at the providers' perception of affordability of cost. As one provider P8/D said, "The cost of the treatment is affordable in case a couple want a child. It is a myth that it is very expensive and unaffordable."

As P18/H said, "It is not at all costly. Anyone, even a rickshaw puller, can afford it. Just think of us, even we have to spend a lot on maintenance. We have to think of ourselves also. Why doesn't the government provide these services?"

The providers expected the government to reduce the cost of the drugs, which in turn will reduce the cost of treatment.

P2/D said, "The cost of drugs exceeds the cost of the procedure. Hence the government should play an active role in bringing down the cost of the drugs – by reducing sales tax, manufacturing drugs in the country and making these techniques available in the public sector."

P13/M said, "The cost of the treatment becomes expensive because of the drugs, which need to be imported. The government can play an active role in bringing down the cost of the treatment. A lot of people lost their children during Tsunami and most of them had undergone sterilisation due to government's fierce sterilisation drive. The government now as part of their Family Planning Programme should ensure that these people also have a child through these techniques."

Some of the providers also said that they were running charitable Out Patient Departments (OPDs) in order to provide access to people from all classes. P20/H shared an "innovative" way of treating poor patients: "I don't go for costly drugs as many patients cannot afford it. Sometimes medical representatives get drugs, which do not have good sales. I take those drugs from them and test it on patients. It's like a trial. But by trial, I don't mean something like animal testing. I use these drugs for poor patients. This way the medical representatives are happy and the poor couples are also happy."

There is lack of standardisation of the cost of the treatment and it depends on people's ability to pay. Whereas the poor people have the potential of being abused through the use of "drugs which do not have good sales", the rich are also vulnerable because they might be the ones who end up paying much more than is necessary. This arbitrariness in cost of treatment however, cannot be said to be the feature of ART industry alone, but is applicable to the unregulated private health sector in India. However, the field of Assisted Reproduction is unique in the sense that it capitalises on individual vulnerability and the social pressure to have a child.

7b. Women's views on the costs involved

Of the 25 women interviewed, only 18 spoke about the costs involved in the procedures.

As W22/H cited, "I don't know how much the treatment costs. My husband keeps track of it." Another guessed that, "It's less expensive here than in the U.S."

Two of the women stated that the cost of IVF (a single package) varied between Rs. 1,00,000 to Rs. 1,15,000 but the total cost amounted to Rs. 2,00,000, if expenses on diagnostic tests prior to the procedure were also included.

One woman who underwent IVF-ICSI quoted the cost to be Rs.1,00,000 per cycle. However, there was a reduction in the cost (Rs. 50000) in the second consecutive cycle since the procedure was done with the cryopreserved egg. W11/D, who had undergone five cycles of IUI, one IVF and two IVF-ICSI cycles, said that the total cost had escalated to Rs. 8-10 lakhs.

Two women said that the money spent on different diagnostic tests, ultrasound, consultation etc amounted to Rs. 30000-60000.

The cost of the procedures, which was generally quoted by the providers, did not usually take into account the cost of the diagnostic tests like laparoscopy, ultrasound, consultation fees, drugs and injections etc. Neither did the costs take into account the money spent on travel, accommodation in the city if the woman was coming from a different city, the cost of loss that one suffers in one's own business – these hidden costs of the treatment were being highlighted by women while talking of the costs involved.

As, W2/D said, "There are a lot of costs involved if you include the cost of the laparoscopy, the diagnostic tests, the medicines, the travel cost that you incur, the loss you suffer if you are running a business."

Although IUI is often projected as cheaper (only Rs. 5000-6000), if the costs incurred on diagnostic tests and consultation prior to that (as articulated by women) are calculated, the actual costs may well amount to somewhere between Rs. 30000 - 40000. Two of the 18 women also highlighted the variance in cost between clinics and cities.

The high costs involved for going through the procedure and hence its inaccessibility was exemplified when W4/D who underwent IVF stated, "...we were not able to afford so much money during that time.Finally, last year in June we somehow arranged for the required money."

W9/D said, "We have not kept an account of what we have spent. Almost whatever we have earned has gone into this. But we are not worried about money. *Zamin jaidad hai to kis liye?* (What do we have land and assets for?)."

The same point is reiterated by W24/H, "The treatment is expensive but it is worth the result."

The cost of the process that women spoke about did not limit itself to the actual cost of the treatment but brought out the hidden costs as well. There was a general feeling

that these techniques were expensive and they drained and exhausted the resources of the women. At the same time, costs were weighed against the "product" that it promised to deliver and once the risk benefit analysis was done, even expensive treatment became "affordable".

W5/D – "There is a lot of money, time and energy that we are spending. But this is nothing when compared to holding your own child in your hands."

W8/D - "We were not so financially burdened since both of us work in government hospital and are reimbursed for the entire cost. Only the rich people can otherwise afford the treatment costs."

Section 8: Expectation and experience

This section describes the expectation and experience of the "desired" child. The section includes the providers' perspective on the "desired" child; donor profile and recipient couples' expectation; and related/unrelated donor.

Providers' perspectives on the "desired" child

Women who were going through these techniques spoke of the desired child as the ultimate goal. However, their desire to have a child was so intense that neither the sex of the child nor the characteristics were specified nor sought. Among the 25 women interviewed, none of them claimed to have gone for IUI or IVF using donor eggs or donor sperm. However, some of them said that they had met other couples in the clinic who had gone though donor programmes. However, nine providers spoke about the characteristics that recipient couples look for in donors. These articulations gave us some indication about the traits, which are desired and valued in society and the expectation of having those traits in the child, as the technologies provide the scope for this.

Providers on donors' profiles and recipient couples' expectation

Among the 10 providers who spoke about profile of egg/ sperm donors, five specified that the ideal age of the donor should be between 20 to 30 years. Four of them said that the sperm donors are generally students. One specified that they are also medical representatives whereas one provider said they are from working class.

P9/D specified that, "We have developed relationship with our donors. There are some men who have been donating sperm from the time they were students. Now they themselves are married and settled."

All the providers who spoke about egg donors felt that, "The egg donor should be in the age group of 20 to 35 years with having two healthy children." Three providers strongly said, "We discourage eggs from virgin female. The woman should be married and at least have two children." One of them though discouraged them for medical complication that they may have in future. The articulation of the two others were more guided by their notions of morality in who should donate eggs rather than medical reasons. "Some young women are selling their eggs but, by doing this the right kind of culture is not being promoted. Women selling eggs for money is primarily a Western concept, which should not be blindly followed by us."

As to which class of women are coming forward to become egg donor one provider, P15/M replied saying, "Some claim that we have high-class women coming for egg donation. Which high-class woman will come and donate? They are housewives doing small jobs. The women should be physically fit, should be below 35 years of age and have two children." Whereas, the other, P22/H said, "It is difficult to get educated egg donors as it requires the woman to be given drugs and anesthetised to remove eggs. The process is complex and those who are usually willing to go through this are from poor families."

These two responses can be taken as a pointer to show us how there is a high probability of women from lower class becoming the suppliers of reproductive "material".

Providers on related/ unrelated donors

Three providers felt that it is better to have egg donors who are related to the couple as, "It is a complex process and the woman has to be monitored for 15 days. There is a lot of commitment from the donor." One of these three providers however, felt that, "Recipient couples are often hesitant to get egg donor from relatives for future complication in the family." The rest of the providers felt that it is better to have unknown donors both in case of sperm / egg donors as couples do not prefer known donors.

In case of sperm donors, where most providers claimed that they get it from sperm banks or recipient couples get it from someone in the family, one provider felt that, "There are a lot of problems involved in case of donor sperms. If a man donates sperms for his brother, later on he may come and claim that it is his child. It complicates relationships. There was a case where a woman wanted to use her sister's egg and her own husband's sperm to be implanted in her own uterus. But the sister wanted the sperm to be of her husband. So basically, it would be the sister's and the spouse's child which she would carry."

These concerns by the providers about related / unrelated donors throw light on the how couples negotiate their desire for a child while at the same time being conscious that such negotiations tread upon existing relationships, in the most unobtrusive and minimal way. This is important so that questions regarding "ownership" of the child do not arise in the future. Another concern regarding this has been articulated by P8/D who said, "Related donors pose issues of incest. There are also concern about inheritance and also with the fact that the child grows up in proximity of genetic parents."

As P2/D shared, "Social norms define choice of the donor. In ranking order of priority, it is fair, well educated, resemblance with parents (colour of eye, height)."

It is worth noting that eight out of nine providers said that the recipient couples look for sperms/eggs from fair skinned donors. Some of the other characteristics that were specified by them were, "intelligence, good looks, healthy, educated, same religion and caste."

As P8/D said, "There are demands for fair skin. In one instance an Indian couple living in Kuwait, who are themselves dark skinned, wanted a fair skinned child. In another instance a couple wanted sperm from a fair skinned man even though the husband's sperm was okay."

The overwhelming concern for the recipient couple as articulated by the providers was that the child should "look as if born from wedlock." On the one hand, there was an articulation of characteristics, which were accorded high value in society and a demand for them. There was also a concern to maintain the integrity of the marriage followed by childbirth so that the outside world did not know that there had been an "artificial" process involved and that the triad of the man, his wife and their children had been interrupted. The notion of the "designer baby" may not be the language with which these characteristics were asked for, but these were steps towards that end. These notions of what characteristics are valued and prized in society are so imbedded in the cultural norm of the society, that the articulation of the same often does not entail conscious thoughts on the part of the recipient couples.

Two providers said, "We do not entertain choice in this regard" and "only essential characteristics are matched and feature to feature matching is not done." However, the brochure of the clinic of one of these providers clearly states, "The donor's physical characteristics are matched with the recipient in terms of height, physique, colour of skin/eyes/hair, texture of hair, caste, religion, IQ, blood group, general/financial status in the society." There maybe two reasons for this

contradiction in the interview and in the brochure. The provider may have wanted to be politically correct while saying that "choice in this regard" was not "entertained", while the brochure, which is the tool for marketing the clinic, plays on the mentality of desirability that the recipient couples often have.

Two other providers said, "We assure patients that we are not getting sperms from rickshawallahs and get sperms from men of good families." One of the providers also said that they try their best to match religion, whereas the rest said that the characteristics that were matched were – physical features, colour, height, family background and educational background.

It was interesting that the providers' perceptions of what essential characteristics needed to be matched, in most cases, echoed what was desired. The fact that providers were also part of the same society and imbibed the same values prompted them to think that these characteristics were essential to match. Underlying this thought process was not only the need to satisfy the client's requirement but also the belief in genetic essentialism and constructs of "good" and "bad" gene, depending on familial and social background. This made them believe that rickshawallahs' sperm was something inherently inferior. Thus, what was being promised by ARTs was the reproduction of a baby of one's choice. It was the promise to enable reproduction of a baby of the appropriate caste, religion, class, and physical characteristics.

Section 9: Men's and women's responses to diagnosis/ treatment

This section is titled, "Men's/women's responses to diagnosis/treatment." It is subdivided as follows:

a. providers' perspectives on responses to diagnosis/treatment
b. experiences and perceptions of the process as articulated by the women; the impact on their life (general routine, work pattern and sexual life)

9a. Providers' perspectives on the responses to the diagnosis and treatment

Although the study concentrated on women's perceptions and experiences, providers articulated the gender difference in responses to diagnosis and treatment. Among the 10 providers who talked about it, eight felt that either men "deliberately suppress their problems" or they "are not forthcoming for tests or treatment", since they perceive it as a "threat to their maleness". Even men who had come for treatment generally go through a lot of negotiation and as P2/D said, "If a man is diagnosed with 'the problem' you would be able to make it out from his face – there is so much anxiety on his face."

Of the remaining two providers, one felt that, "Men are coming for treatment but they are not forthcoming for treatment on ejaculatory disorder. Some do agree but a lot of thought goes into it before they decide." The other provider felt that, "There has been a change in the attitude of men using these procedures." Two contrary examples were shared:

"A couple where both the husband and the wife are highly qualified and are being treated for infertility. They started with IUI, and the semen test of the husband showed that the quality of semen was very bad. Therefore, now they are trying to have a baby through IVF. One day he visited me alone and confided in me that he was open to taking recourse to donor insemination as the problem was with him. In contrast to this, there is the case of a poor Muslim couple from Bihar who has not been able to start their own family because the husband had some kind of problem. But he does not want to have a donor for this purpose."

These two examples bring out the different responses to infertility diagnosis and treatment. They also clearly reflect the stereotypical image of educated (probably Hindu) "modern", "metropolitan", "middle class" men vis-à-vis a "poor" Muslim man and the provider's perception of how each of these categories of men then negotiate their understanding of manhood. What is important in this stereotypical understanding is acknowledging the fact that both men came for infertility treatment and that the "highly qualified" man also came to the doctor alone and not along with his wife to consult about donor insemination.

However, more than highlighting a stereotypical religion, class and educational dichotomy, this statement throws light on the secrecy surrounding donor insemination in particular and accessing infertility treatment in general. As P2/D remarked, "Sometimes the woman would come on her own and would ask to do donor insemination without the husband's consent."

This difference in response of men and women to the diagnosis of infertility, stems from the fact that even today, the onus of child bearing and thereby the failure to do so, to a large extent falls on the woman. Man's incapability to father a child is so inherently linked to his "manhood" that the remotest chance of him having the "problem" threatens his identity. The anxiety around "potency" as determining and proving one's masculinity, becomes relevant to the understanding of the specific responses to fertility treatment.

9b. Experiences and perceptions of this process as articulated by the women

"I don't know when this process will end – I feel like I am caught in a corked bottle and thrown into the sea and I am desperately trying to come out of the bottle and then out of the sea – but don't really know how."

—A woman during the interview[11]

Seventeen women shared their experiences and perceptions of the treatment. Eleven of them expressed that the treatment, above all, had been "mentally exhausting", "tiring", and "frustrating".

As W11/D said, "What has been really difficult in this entire process is that it has been mentally exhausting. I am generally a person with a fighting spirit but I have gone through moments of utter desperation and depression and I feel that the world has come to a halt. Once the IVF cycle fails, you feel utterly dejected and don't really know how to explain the whole thing to yourself and others. You feel frustrated. It is definitely not easy going through this process."

Two women said that there was a lot of tension only in the initial years of treatment and later it became a routine, like the treatment itself.

W6/D shared with us her experience of going through the treatment: "The process itself has been mentally straining and emotionally draining. We only think and hope that one day God will listen to us. We have come all the way from Kanpur. That in itself consumes so much time and money and energy. We also have to bring our child who is not normal and leave him at a relative's place. We can't take him every place we go. But the doctors don't understand all this. They just ask you to come and then once we are here, they say everything is okay and we can leave. The last time I was here, they said I had to go for an Oral Glucose Tolerance Test (OGTT), i.e., some kind of an insulin/sugar test. If the report is positive, then I have to take Metformin. When I called up to check the result of the test, the doctor got angry and asked me to come and visit her and not to inquire over the phone. She also said to start the medicine. If they can start the medicine without the report, then what was the need to ask me to go in for the test? It's just a waste of Rs. 2000. What's it to them? They do the test as a routine procedure. They don't understand our problem. She is so busy that there is no time for her to listen to our problems or explain anything to us or even talk to us. We also don't have the full information. But please don't tell this to her. The report is not even ready today, which means I have to stay back another day and collect the report tomorrow. I also want to show it to the doctor because it does not make any sense to go back without that."

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11 Articulated by one of the women interviewed during the course of the study.

The remaining six expressed their dissatisfaction with the providers or blamed their own luck in not being able to conceive, whereas the rest refused to talk about the experience at all.

As one of the women W10/D remarked, "They leave half the things unsaid or they say it in a way that seems very simple. Only the one who is going through it understands the pain of it. When they were doing the laparoscopy, they said that it would entail a minor cut. But when they actually did it, it was so painful. I could not get up from the bed for the next two to three days."

One woman among the six also mentioned the difference in treatment modalities in different cities. As the women's perception ranged from either looking at it as a "gamble", "a trial and error science", or its success being dependent on individual luck, fate and God's will.

The narratives were thus, interspersed with looking at treatment as scientific but also as something guided by luck and fate.

As W12/D articulated, "The laparoscopy and series of ultrasounds every month make you feel so much resistance towards these. Every month you hope, and become tense that you will skip your menstruation and conceive. It is a feeling of complete helplessness when you have your menstruation, you can't even explain it. You have only 12 chances of conceiving in a year, and suddenly this seems so less and restricted compared to men who can produce a child everyday. It is very important to have a positive mental attitude, otherwise it becomes very difficult to remain stable mentally as you go through the entire process. Patients like us who have been undergoing treatment for quite some time now and have been going from one doctor to the next, understand quite clearly that this is trial and error science."

Another woman, W9/D, questions science in itself and tries to juxtapose it with the mythology of creation; "They say science has progressed but I don't understand, with my limited knowledge, how it has progressed. Even during Mahabharata, Pandu, Dhritrashtra and Vidur were all sons of Vyas Muni- isn't it so? Even Pandu's sons were born of different gods. I am really at my wits' end."

The experiences of going through this process have been a constant negotiation of hope, frustration and desperation to go on till the end. Sometime, there has been frustration at "nothing happening", at failed cycles, at the insensitiveness and busy schedule of the doctors, at wrong diagnosis and piecemeal information, but at the same time, there is also a zeal to succeed. Although there is a recognition by most women that the

techniques used are experimental, the responsibility of failure in most cases has been attributed to individual luck and fate. There has thus been an intermingling of medical and socio-cultural language to understand the process and also to gain a "new" understanding of the body and the process of reproduction. While the "newness" of science has been questioned by drawing parallels from mythology, there has also been an unquestioned hope that scientific intervention would create "miracles".

Impact on Life (General routine, work pattern, sexual life)

"A woman whose identity is closely tied to being a mother..., feels the burden of infertility constantly. Her sense of herself as a sexually desirable person becomes distorted. She suffers feelings of inadequacy and may experience herself as unlovable, damaged or defective. Her life may seem purposeless."

—Susan Cooper[12]

Of the 25 women interviewed, 12 did not say anything about the impact of treatment on their general routine, work pattern or sexual life.

As W2/D said, "It affects my work pattern and my business suffers as I have to come to the doctor very frequently. However, if you don't have a baby and you really want one, you have to accept and agree to go through certain things you wouldn't go through otherwise. If you want something, you have to bear the cost of getting it."

Three women said that it had affected their general routine only. As W3/D said, "During that phase (of going through IVF), and even before that, I would come in the morning without eating, for some tests that needed to be done. The report would be available only in the afternoon, around 4 p.m. It made no sense to go back as it takes one, or one and a half hours to come to this place. So, I would sit the entire day, bring my roti and eat here. The next course of treatment would depend on that report so there is no other choice but to wait. No doubt, we have spent a lot of time and money on this. But, what other option do we have?"

Four of them said that it had not affected their work or general routine but felt that it was so because they were not working. However, they said that the routine of their husbands was affected as they had to accompany them.

W1/D said, " I am not working so I can adjust and come over whenever the doctor calls me. However, it disrupts the routine of my husband as he is an aspiring software engineer."

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12 Susan Cooper, Paradise Lost: Sexual Function and Infertility

One woman W5/D said that the treatment affected both her work routine and sexual life, but only in the initial years - "In the initial years, when the doctors told us that we should try conceiving naturally…it became very pressurising to have intercourse in that time frame. But now that we know that we cannot conceive naturally, the pressure is not there."

W12/D said that the treatment had affected not only her work but also her general routine and sexual life. "Let's accept it that the process is very frustrating. You don't have sex because you want to. But you have sex because you have to. Once I conceive, maybe I won't "do it" at all. The amount of sex we have now, we did not have when we were not planning to have a baby."

However, W5/D said, "I realised that my husband was impotent and that we can never have sexual intercourse. I cannot tell you what my experience was at that time. I was totally shaken. I also had certain expectations from my marriage. Moreover, you cannot deny the sexual urges that you have. After all, you are a human being with biological cravings."

In these narratives, multiple trends of thought have emerged. For some, going through this process has affected their general routine, work or sexual life. However, most have weighed this disruption against the pleasure and need of having a child (which has also emerged in other contexts of costs and experiences). Women who were self- employed or working, articulated that "frequent visits to the clinic", "waiting for long hours", "travelling long distances" etc. affected their work. However, those who were not professionally engaged, felt that their work and general routine could be compromised vis-à-vis their husbands'. They did not perceive their household work as important enough compared to their husbands. It was also felt that going through this process had impacted their sexual life, which had become a mechanical way of procreation under the medical "gaze".

However, women who had been going through this process for a long period, felt that the process had become a part and parcel of their daily routine, and had become the axis on which their life now revolved. These impacts of the treatment on their lives and routines of the women involved, brings to the fore the invasive and all-pervasive nature of the ARTs. The treatment is not restricted to the clinic alone, outside which one's daily life can be reclaimed. On the contrary, the treatment claims the entire time and various aspects of the lives of its women. Even one's professional life is not spared by the process. Moreover, the most private aspect of one's life—sexual relations, are also not beyond the scope of the panoptican "gaze" of the treatment.

Thus, some of these procedures take the spontaneity and privacy out of sex by subjecting the act to the medical "gaze". Thus, sex for them, begins to resemble a clinical procedure. They are required to maintain a chart of their sexual activities, which is then studied by the doctor to improve conception chances. Often, doctors admonish the couples for not having sex frequently enough. Such procedures magnify feelings of invasion and it may also be humiliating for the couples to discuss their sexual conduct.

The mental disturbance experienced by the women during the process, may be attributed somewhat to the constant surveillance that they are under, which is further magnified by the pressure of performance.

CHAPTER 4

Commercialisation

"Advances in reproductive medicines have indeed created a market for babies, a market in which parents choose traits, clinics woo clients, and specialized providers earn millions of dollars a year. In this market, moreover, commerce often runs without any rules."

—Debora L.Spar[1]

Economic globalisation is no longer restricted to goods but now includes services as well. Medical services are the latest addition to the list of services that are increasingly becoming commercialised. This has resulted in a phenomenal growth in medical tourism, with people traveling across the globe to use these services. India is the newly emerging lucrative destination for these medical services including techniques of assisted reproduction as it offers these procedures at a relatively low cost.

In this section, we discuss the commercialisation of ARTs because these technologies have varied implications for women. We review the implications of commercialisation of ARTs in India. It is interesting to see the impact of globalisation in a country regarded as developing, and the manipulation of the social norms to further profit making interests.

Growth of the ART industry

India now has the fifth most privatised health sector in the world and is being seen as an attractive destination for various medical procedures, including techniques for assisted conception. According to an article published by the magazine Outlook, medical tourism is slated to become a $2.3 billion industry by 2012, next only to the Information Technology sector[2]. In a joint report, the Confederation of Indian Industry and McKinsey Consultants estimate that there is a staggering 30 per cent growth annually in medical tourism in India and this could become a $1-2 billion business by 2012.[3] These figures

1 Debora L. Spar quoted in , The Hidden Market for Babies, HBS Working Knowledge, 13 February, 2006 http://hbswk.hbs.edu/item.jhtml

2 Anjali Puri and Payal Kapadia, Carry on Doctor, Outlook, February13th, 2006,

3 Express Pharma Pulse November 15, 2005

indicate the huge potential of the Indian market for medical tourism. The Indian government, and private hospitals endorse and promote this process by offering easy access to financial incentives like low interest rates, special "medical visa", subsidised rates for buying drugs, etc. There is virtually no end to the perks and incentives that are being offered to the providers of these technologies to bring their expertise and business into our country. In this scenario, there is a real danger that the interests of women undergoing these procedures will be neglected.

The Government has introduced various policy measures to further encourage medical tourism. For instance, the National Health Policy recognises the treatment of international patients as an export, which allows private hospitals treating such patients to enjoy benefits such as lower import duties, increase in the rate of depreciation (from 25 per cent to 40 per cent) for life-saving medical equipment, and several other tax sops.

Source: Nithya Subramanian and Ashwini Phadnis, Govt plans to promote medical tourism from Oct, New Delhi, August 15, 2005 www.thehindubusinessline.com/2005/08/16/stories/2005081602310300.htm

The growth of medical tourism is not confined to services like knee replacement, heart surgeries and eye treatment. ARTs are the latest addition to this ever-growing list of services.

"B in BPO is birth"[4]

The increase in medical tourism in developing countries, especially with respect to ARTs, largely results from the fact that these treatments are cheaper here. IVF clinics in India have further cut costs, thereby attracting more and more foreign couples, not only from the Asian diaspora and African countries, but also people from the developed countries like UK, U.S., Canada and Australia, to name a few. This catering to the foreign population enables a comparison between the ART industry and the Business Process Outsourcing (BPO) sector, with services being constantly outsourced.

With an influx of foreign medical tourists, infertility clinics in India have mushroomed and this has become a matter of great concern. Unlike most other medical techniques, the success rate of ARTs is below 30 per cent under the best of circumstances. The clinics capitalise on the intense desire of infertile couples to become parents by making incredible claims of curing infertility through high-pitch publicity. A conservative estimate of the potential infertility treatment market in the country is over Rs. 25,000 crores per year (2002). A large portion of this money, which is spent by infertile couples (15 per cent), may amount to a complete waste on their part.[5] The high costs and low success rate of these technologies not only tax a couple's endurance monetarily, but also drain them physically and emotionally.

4 Reshma Patil, Test tubes Indian, babies foreign, Front Page, February 29, 2004

5 Modern Indian Frankensteins Abuse Reproductive Technology, Antidoctor, Wednesday, June 2, 2004

Increased medical tourism has made it mandatory for the providers to draw in more and more clients. In this respect, infertility has been raised to the level of a new epidemic, which is fast spreading and needs to be combated now by the fertility industry. This sort of reasoning is used to justify the increasing availability of these technologies. Moreover, providers portray ARTs in a positive light by offering expanding choices for women. However, underlying this rhetoric, providers are marketing the notion of motherhood as an identity that every woman should, rather than can, have. These technologies therefore, cash in on the vulnerability of couples around the issues of motherhood and infertility. The importance attached to a woman's reproductive role provides the context within which the development, proliferation, commercialisation and use of ARTs need to be explained and understood. All that matters is to have a biological child at any cost. In such a scenario, technologies of assisted conception claim to provide new options and hope to infertile couples. Infertility is projected as a disease in need of treatment. Some doctors and experts providing fertility treatment themselves believe that "being infertile can be expensive." In addition, there is danger of infertile couples being subjected to the risk of over treatment. Just because they can afford it, doctors advise them to go in for an IVF cycle, while simpler treatments such as IUI may have been successful.[6]

As treatment procedures in the fertility market become highly commercialised and bodies become commodified, there are huge interests at stake in the promotion of these technologies. Hence, the growth and proliferation of the (in)fertility industry has to be placed within the framework of the globalised economy and the profit seeking systems in which such technologies are being advanced. The spreading of ART clinics from big metros to small towns is reflective of this. However, the type of services being provided and their quality vary to a considerable degree in both rural and urban areas. A fully equipped ART centre in a rural area costs around Rs. 20 lakh and Rs. 40-50 lakh in cities, depending on the cost of the premises.[7] The question one needs to ask is who accesses these treatments and at what costs? Cost here would imply not only monetary expenditure, but also the physical, psychological and social implications of using these technologies.

Real success or marketing

Although there has been a great deal of advancement in reproductive technologies since the birth of the first IVF baby, the real success story of these techniques remains a matter of debate and contention. Successful pregnancies using these technologies

6 Malpani and Malpani, How much does treatment cost? In How to Have a Baby: Overcoming Infertility,UBS Publishers' Distributors Ltd. 2001

7 Express HealthCare Management, February 1-15, 2005, http://www.expresshealthcaremgmt.com

are highlighted, whereas there is near silence with respect to the cases of failures, which are many more. Success rates in this market have been creeping up to as high as 40 per cent to 70 per cent (for young women). Exorbitant success rates can also be found in the brochures and websites of various clinics offering these services as a promotional strategy. The brochures of some of the ART clinics quote extremely high success rates of up to 60-70 per cent. In reality though, successful pregnancy varies vis-à-vis the age of the woman undergoing treatment. With younger women, pregnancy rates can be high, with an expected drop in the case of women with advancing age.

Moreover, often the success rates quoted by the providers are neither the take home baby rate nor the live birth rate. They generally quote the successful implantation rate as the success rate, but a high incidence of miscarriages occur post implantation. Providers commonly attempt to shift the onus of success and failure onto the women themselves, alleging lack of care taken following procedures. This leaves the rosy picture created of these technologies untouched and alleviates them from any responsibility for failure and helps to promote marketing of these technologies.

Advertisement gimmicks

In order to attract couples to use these technologies, clinics and centres adopt well thought out strategies for marketing ARTs through both print and electronic media, including websites that reach out to potential patients globally. Advertisements in some of the websites of different clinics are worth mentioning here. The primary marketing tool used are the exclusive package deals offered to the clients. Even religious sentiments are not exempted from being exploited, used for profit making and attracting a clientele. To cite an example of a fertility clinic in Mumbai, "All Muslim couples will be counselled regarding the proscription of their religion while selecting an appropriate treatment modality. We will ensure that none of the Shariat laws are broken while providing infertility treatment."[8] Moreover, these advertisements, offer the entire treatment procedure as a package, whereby the couples opting for such procedures can get maximum benefits and services if they go for a particular deal. Therefore, all clinics and centres work to provide the best possible offer.

In addition to this, most clinics or hospitals use catchy advertising text to attract the attention of people accessing such services. For example, the brochure of an infertility centre in Hyderabad says, "Life deserves the best... we try to fulfill your need for a Child". Another brochure of a fertility clinic in Delhi mentions, "Dream comes true....

8 http:// www.test tube baby clinic.com

because every couple has a right to have their own child." One hospital from Mumbai claims, "A thousand already born...thousand more to be." The website of a fertility clinic in Bangalore says, "Is your longing for a child unfulfilled? Your search ends here."[9] These are only some examples of the extent to which marketing and advertisements drive forward technologies of assisted conception. With the rampant increase in number of ART clinics, the fertility market has become very competitive and, like any other market, depends on advertising and marketing to distinguish a product from a range of similar products. In a desperate pursuit for one's own child couples go doctor-shopping from one clinic to another or website searching for the best doctor, until a doctor or clinic fulfils their expectations in every respect. Advertisements target precisely this desperation.

Excerpts from the websites of fertility clinics

1. You can book your tickets online, and find the best deals, check out http://guides.usaindians.com/travel/

   A return air ticket to India from the US costs about US $1000 - 1500. Your husband can accompany you, or you can hand carry his frozen sperm in a dry shipper (which you will need to borrow from your local infertility clinic). The clinic is at Bandra, just 20 minutes from the International airport, and is truly in the heart of Bollywood country (Beverly hills of India!)

Source: http://www.iwannagetpregnant.com/moneyback.shtml

2. See Taj Mahal by the moonlight while your embryo grows in a petridish, or Stay in five- star apartment suite while you undergo hormonal treatment cycles.

Source: Quoted in Shree Mulay, New Climate for marketing of NRTs and its implications for regulatory processes, unpublished document, 2006

It is not only the fertility clinics providing the treatment that indulge in marketing and advertising of the technologies, but also the growing numbers of pharmaceutical companies, whose commercial interests benefit from the promotion of the drugs used in these treatments. Hundreds of companies have been started to develop and promote technologies whose benefits are still questionable to a large extent.

There are many examples of the marketing of certain specific fertility drugs solely for profit making. Pharmaceutical companies have withdrawn their relatively low cost from the market in order to create a demand for more profitable drugs. The interests of the persons using these drugs become secondary in such situations. For example, urinary gonadotrophins Pergonal and Humegon were withdrawn from the market, and injections like Gonal-F and Follistin with higher profit margins were aggressively

9 http://baccweb.com

marketed, where providers themselves were influenced by advertising to a great extent. [10]

Moreover, ART clinics distribute brochures in which the social pressure to have a child is extensively used to market the technologies and the clinics. Hence, they attempt to naturalise and universalise a female instinct to procreate. The brochures talk about infertility, technologies and providers, as if marketing a product, i.e., the baby. The "altruistic" providers are portrayed as demi-gods, as they enable the couples to realise their "dreams" through their expertise and efficiency.

Body as a commodified entity in the use of ARTs

The ART industry has also created new commodities and economic equations. Reproductive body parts like sperm, ova and uteri can be treated like any other commodity to make a profit. A market is created of people willing to buy these commodities, and a supply is created, of people willing to sell their body parts. This becomes a cyclical process. This process will surely worsen the exploitation of women who already face oppressions of various kinds; social and economic.

In such circumstances, it is not only the reproductive organs, which attain a price tag and become a saleable commodity, but also, the individuals who sell/donate/rent these organs, with their biological and social attributes as their particular USP. Having certain biological and social traits become the deciding factors in who can be a potential donor. This applies more to women than to the men. Feminists have always been extremely critical of equating and looking at woman's bodies as mere commodities to be used for reproduction and procreation. In commodifying reproduction, an all encompassing aspect of price gets attached to it, and reproduction as a process is commercialised.

This is best exemplified from arguments put forward by Barbara Rothman. To quote her, "Here we are, actively pricing motherhood- it costs about $1,000 to purchase a spare embryo, another $11,000 to "rent a womb," and there we have it. What is the meaning, what the value of motherhood? $11,000 on the open market. And once the priceless is priced, market considerations take over."[11]

According to an article published in Asian Age,[12] enticing advertisements are posted on the websites that offer generous financial rewards to healthy men and women to donate sperms and eggs. The article states that such practices are creating a new breed of donors of young people who are college students or professionals, ready to donate

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10 How to save money on your HMG injections, http://www.drmalpani.com

to meet their economic needs. Both these types of incentives allow the opportunity of exploitation by inducement, of donors.

Just as the techniques for assisted reproduction are marketed and further propagated through lucrative strategies, in the same way, big monetary and other incentives are used to attract persons into the business of selling reproductive parts. It becomes crucial here to understand that advertisements promoting these techniques treat the human body no different from any other commodity, where the best will sell in the market. A fertility clinic in Delhi providing Egg Donation service mentions in its brochure that, "Egg donors must be between the age of 18 and 35 years, should be healthy and have a desire to help infertile women. The donors must be prepared to undergo screening for infections and hereditary diseases. Proven fertile donors are preferred."

Mumbai girls sell eggs

...the reality is that mostly young single women are rushing to donate their eggs. Infertility clinics get four to five calls in a day from young women wanting to donate their eggs.

Most of the college students and professionals who opt for such donations say that they do it for economic reasons. The cost of living in Mumbai is high and a donor gets around Rs 20,000 for donating an egg once...

Pooja (name changed), a young professional says: "I have donated for economic reasons. I was in need of money. I am staying as a paying guest and I have so many expenses that I thought this could be a fast way to make extra money."

Source: Skimmy Gupta, Mumbai girls sell eggs for Rs. 20000, Asian Age, June, 10th, 2004

The extent of commodification of the female body is clearly manifested even in the kind of language these advertisements use. The box below illustrates just one such example.

The website of a fertility clinic in Mumbai says that the prospective egg donor should be young (less than 30 years of age), healthy and should preferably have proven her fertility (by having at least one baby). Apart from these, educational qualifications, physical attributes, hobbies and regular menstrual cycle are also some other attributes in the profile of donors. The same website mentions that one can reserve an egg donor, by making an advanced payment of U.S. $1000. This payment can be done online by using a credit card.[13]

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11 Barbara Katz Rothman, Reproductive Technology and the Commodification of Life, in Embryo Ethics and Women's Rights, Harrington Park Press, New York, 1988

12 Skimmy Gupta, Mumbai girls sell eggs for Rs. 20000, Asian Age, June 10, 2004

13 http://drmalpani.com

Egg Donor for Fertility Treatment

Looking for lady less than 35 years of age, willing to donate her eggs for fertility treatment. High confidentiality, world-class health-care in a well-known hospital. Suitable remuneration assured.

Source: Women's Era, June, 2006

Social norms define the choice of donor. In ranking order of priority it is "fair, well educated, resemblance with parents (colour of eye, height)." The overwhelming concern with regard to the patients, which the providers mentioned, was that the child should " look born from wedlock." There is significant concern to maintain the integrity of the marriage followed by childbirth so that the outside world does not know that the child has been born as a result of artificial techniques.

Our analysis of 33 surrogacy related advertisements appearing in two women's magazines in English and Hindi brought out the following eligibility criteria for surrogacy:

- 40 per cent of advertisements specified the looks of the surrogates desired. Fair, good-looking, beautiful were the traits the intended couple were looking for.
- 15 per cent specified the marital status of the desired surrogate, which was broad, ranging from single, widowed, separated, unmarried etc.
- 66 per cent of advertisements specified that the surrogate should be healthy or free of any disease.
- The average age desired was 25 years
- Almost all advertisements specified that rewards and secrecy are assured.
- There are also references to the surrogates having good moral values, good background.
- 10 per cent of advertisements specified the caste desired.

The examples of various websites, advertisements and brochures discussed, clearly reflect the conversion of human bodies into objects for sale and use. There is almost little or no consideration about the effect of these technologies on the lives of women, though it is they who undergo invasive medical probing, drug programmes, and surgical interventions. Medical research is determined in its efforts to give a successful childbirth and women's bodies are visualised only as a means to achieve a successful end.

The contractual market of surrogacy

From the much used technique of IVF to the process of surrogacy, where a woman rents her womb to an infertile couple, the use of techniques for assisted conception have come a long way. The entire process of surrogacy, starting from advertisements to delivering the baby, is the classic case of ARTs being commercialised and commodified. Though

14 Malini Karkal, Surrogacy from a feminist perspective, www.ijme.in

the practice of surrogacy has existed for a long time, in recent years, it has become a huge means to earn money, cutting across geographical boundaries.

The process of surrogacy turns the normal biological function of a woman's body into a commercial contract. Services for surrogacy are advertised, and surrogate agencies make large profits in recruiting and providing/arranging the services of surrogates. Just as in the case of other donors, the selling point here too is "quality" of the surrogate, which is determined by social background, looks etc., and, preferably, by proven fertility. The advertisements for surrogacy are exemplary in driving this point home. Advertisements in magazine read, "Good looking, fair, 27-year-lady from respected family available for surrogate mother. Only rich and genuine people contact."

Our interaction with the surrogacy agent also reiterated this fact. He told us that there is great emphasis on the looks of the surrogate. Most couples wanted a fair, beautiful girl from a middle class background. He said, "I got contacted by a south Indian girl willing to be a surrogate but I could never find a matching couple for her though she is healthy. It's difficult because she is dark." Regarding the cost, he mentioned that the recipient couple pays about 5-7 lakhs for the entire process. The surrogate gets paid around 2 lakh and the rest is spent on the medical expenses and the agent's fee etc. The payment is made on various levels and there are lawyers to draft out contracts for the couple and the surrogate.

The commercialisation of surrogacy raises fears of black market and baby selling, turning impoverished women into baby producers and the possibility of selective breeding at a price.[14] What is critical is to understand how the money changes hands, what the "deal" has been, and what has been spelt out in writing. Issues, such as, who "owns" the child born out of surrogacy have always been a contentious ethical debate. Indian couples usually identify a surrogate mother through the doctor at the infertility clinic and through advertisements. The woman who agrees to be a surrogate, signs an agreement of consent on a Rs.100 stamp paper.[15] The driving motive for the couples to go for surrogacy is to have a child who will carry their "own genes".

The profitable business of ARTs and sex-selection

As more and more couples access these techniques globally the fertility market has taken choice to another level whereby couples not only conceive, but can also choose a child of the desired sex and characteristics. The ART industry also plays on the desire for the "perfect baby" by encouraging women to use these techniques

15 Nandini Oza,To Let Wombs, The Week, July 9, 2006

to filter out perceived defects and choose socially desirable characteristics of their future children.

In recent years techniques such as Preimplantation Genetic Diagnosis (PGD), originally meant to screen any genetic defects, have been openly and extensively used to selectively screen female embryos. It has become a huge market without much regulation. Leading magazines such as Fortune have estimated a U.S. market between $200 and $400 million annually for methods such as MicroSort used for sperm sorting. Regardless of their high price tags, invasiveness, and risks, demand for these methods seems high. Some surveys have also revealed that in the U.S. the proportion of all parents or prospective parents who would use sex selection (if available) is about 25-35 per cent.[16] The procedure of sex-selection has become a huge business in itself, especially in countries where a lot of premium is placed on sons. The societal and emotional normative desire of having a son makes some couples desperate to use such techniques and spend substantial amounts of money to do this. Couples from around the world, including India are spending around $19,000 (about Rs.8.55 lakh) in U.S. clinics for gender selection treatment. These couples are from countries where selecting the sex of the foetus is illegal.[17] Not only the sex of the child, but it is a possibility now also to choose characteristics such as eye colour and hair colour. The Times of India, August 7, 2006,[18] reports that infertile couples can now have "tailor made" babies from world's first human embryo bank, which has been set up recently in UK where for around 5,000 pounds, couples can buy readymade embryos matched to their specific requirements. The report also mentions that there has been large-scale condemnation of such practices from ethical campaigners. They see this as "absolute commercialisation of human life" where babies are treated at par with a supermarket's special offer.

Economics of ARTs

It is difficult to arrive at an exact figure on the cost of the market for reproductive technologies. However, it is evident that over the years there has been a substantial increase in the overall cost of the ART market, where more than the technologies, it is advertising and marketing strategies that play a crucial role in driving this market forward. As mentioned earlier, one of the main reasons for India emerging as a big market and attracting business from other countries is the cost advantage vis-à-vis other developed countries and the quality of treatment. In U.S. there are 200

16 Rajani Bhatia, Rupsa Mallik, Shamita Dasgupta and others: Sex Selection, New Technologies, New Forms of Gender Discrimination, October 2003

17 Making of designer babies, The Hindu, May 16, 2006

18 Designer baby for 5,000 pounds, The Times of India, August 7, 2006

treatments per million inhabitants. In the UK, 76 centres perform more than 30,000 (IVF) cycles a year, and 80 per cent of IVF procedures are carried out in private sphere, while only 20 per cent of it carried out within National Health Service. Some data shows that the cost per successful pregnancy in India is Rs. 250,000 while in the U.S., the cost estimates range from $60,000-$8,000,000. India is a 4,000 crores potential market with a Rs. 400 crore middle class market.[19] Information from some other sources reveal that an *in vitro* fertilisation cycle in the U.S. costs around $20,000 (approximately Rs. 900,000) as opposed to $2000 (approximately Rs. 90,000) in India. In clinics in the UK, a cycle of treatment costs up to 3,500 £ sterling (approximately, Rs. 280,000).[20]

India also has emerged as a preferred destination for couples in search for surrogates. Cities like Anand in Gujarat, and the city of Mumbai have recently been in the news for the staggering growth in the number of surrogacy cases there. The main reason for this is the low cost for the complete procedure of surrogacy, which is a fraction of the cost of similar processes in developed countries. According to estimates provided in The Week in 2006[21], "India has 350 ART clinics, and approximately 1 lakh IVF cycles are performed every year. Even if only around 3 per cent of infertile couples would need to hire a womb, surrogacy – including IVF cycles at Rs. 65,000 – Rs. 90,000 and the carrier priced between Rs. 1-3 lakhs- should be worth thousands of crores of rupees."[22] But experts believe that it is difficult to arrive at the exact worth of the surrogacy industry because of the absence of stringent regulatory or registry mechanisms. In India,[23] a surrogacy including IVF would cost up to Rs.5 lakhs. In the U.S., surrogacy, without ART procedure, alone would cost $15,000. In the UK, an IVF cycle costs around 7,000 pounds sterling and the surrogate about 10,000 £ sterling.

For those who are critical of or unable to afford these treatments because of the high costs involved, the fertility clinics also provide the option of going through egg sharing programmes, wherein a woman donates her ova to another woman, in exchange of treatment costs. For instance, an advertisement of an IVF centre announces, " if you are a young fertile woman, who wants to go through IVF but cannot afford the treatment, you can consider donating your eggs and registering for free treatment."[24]

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19 Amit Sen Gupta, Babies for Profit, (unpublished draft document, 2006)

20 All for a baby, Indian ovum in great demand, Hindustantimes.com, January 10, 2006.

21 Nandini Oza, To Let Wombs, The Week, July 9, 2006

22 ibid.

23 Ibid.

24. Hindustan Times.com, All for a baby, Indian ovum in great demand, January 10, 2006.

Conclusion

In the absence of any proper regulation and legislation, the infertility market has all the making of a well-organised industry and a major source of making money. Since most of these technologies are provided within the private sector, profit making becomes the driving force. With a growing market for the reproductive technologies and its increasing commercialisation, the need to monitor and regulate the infertility clinics has become very important. With countries like the UK and Canada having some mechanisms for regulating and monitoring, the focus has shifted to countries like India, where the prices are lower and regulations are not that stringent.

The regulation and monitoring of these technologies must also be understood and located within the political economy of both developed and developing countries. The government plays a balancing act between promoting medical tourism and trying to regulate the ART industry. Regulation gets the worst of this deal, but there is no doubt that the industry must be regulated in order to protect the interests of those who use its services. Ethics must not be compromised in order to promote commercial interests.

CHAPTER 5

Ethical issues in ARTs and the status of regulation

This chapter attempts to address two important aspects of the research. The first part looks into the ethical implications associated with in *vitro* fertilisation, embryo transfer, surrogate motherhood, and their implications on women through available literature. The second part tries to understand the status of regulation and provides a critique of the National Guidelines for Accreditation, Supervision & Regulation of ART Clinics in India, 2005, developed by the Indian Council of Medical Research (ICMR) and the Ministry of Health and Family Welfare (MOHFW).

For many couples trying to have children, ARTs represent a chance to fulfill their dream of a complete family. However, the inherent nature of many of these techniques and the specific context in which they are used, raises many ethical concerns. Thus, there is a need to understand the ethics of ARTs within the social context in which they operate.

Part I: Ethical concerns

Introduction

The use of donor insemination, oocyte donation, sperm donation or IVF to have a biologically related child can subject the woman to many health risks. It can also create other concerns. These processes of conception through "third party" involvement challenge the social importance given to the conjugal relationship. It also forces one to view the parent-child relationship in a new way. It is worth thinking about whether the legal structure in India will be able to sustain these new changes.

Gamete donation

Gamete donation is a method that enables couples without healthy sperms and/or eggs to conceive.[1] Friends or family of the couple may offer to be donors or the

1 Family Members as Gamete Donors and Surrogates: Ethics Committee Report: Fertility and Sterility Vol 80, No 5 November 2003: http://www.asrm.org/Media/Ethics/family_members.pdf

couples can go for anonymous donation. Many couples prefer familial donors as it enables them to have some sort of genetic link to the child and reduces the risk of sexually transmitted diseases.[2] For example, a brother may prefer his brother to donate the sperm as he may feel that he will at least have some genetic link to the child. However, some argue that intrafamilial gamete donation may lead to situations in which the child would have the same genetic relationship to the participants as children would of incestuous unions between first degree relatives.[3] Another concern raised in familial donation is that the donor may be coerced or manipulated by family members to donate.

Gamete donation also places the donor under physical and emotional stress. Unlike sperm donation, which is a relatively simple procedure, oocyte donation is longer and more complicated. Thus, providing huge financial rewards in exchange of oocytes may encourage many women to undergo the retrieval procedure for financial reasons without understanding the physical and psychological burden associated with it. Women donors who generally provide reproductive tissues or services usually belong to lower socio-economic backgrounds, whereas the recipients are generally more socially and economically advantaged.[4] In a country like India, where poverty is rampant and people are forced to sell organs to raise money, this can lead to widespread exploitation of women.

Oocyte sharing between women undergoing ART treatment brings the possibility of added burdens. Few oocytes available for the initial IVF cycle reduce the chances of pregnancy and the donor may have to undergo additional superovulation, thus increasing health risks. Donors also have to undergo additional medical screening.

Another concern is that payment for oocytes implies that they are property, thus devaluing human life. A high payment, especially for women with special characteristics, conveys the idea of oocytes as commercial property or commodity that tend to objectify children rather than assign them intrinsic worth and dignity.[5]

Embryo donation

Usually, during the process of IVF, the woman is implanted with two to four embryos. Often the oocytes that remain are fertilised and preserved for future use. Before treatment begins, couples are supposed to give in writing what they would

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2 ibid

3 ibid

4 Laura Shanner and Jeffrey Nisker: Bioethics for Clinicians Series: Reproductive Medicine CMAJ May 29, 2001; 164(11): http://www.cmaj.ca/cgi/content/full/164/11/1589

5 Financial Incentive in Recruitment of Oocyte Donors, Fertility and Sterility, Volume 82, pp 240-244.

like to do with the spare embryos. They can be frozen, discarded, donated to other couples or used for research. There are many ethical issues related to the status of these embryos.

One of the main concerns is related to the extra embryos after the couple has conceived. Many of these embryos remain frozen for years, stored for future use. A majority of the reports state that using thawed embryos does not have an adverse effect[6] but the background radiation may increase the mutation rate.[7] Also, clear provisions are not available about what happens to the embryo if the couple divorces, or dies, or loses interest in having a child. Thus, freezing embryo without a specific time or a specific purpose condemns them to a state of suspended animation.[8]

A couple with spare embryos can donate it to another infertile couple. This is generally referred to as embryo adoption.[9] Many doctors who take part in this procedure feel that it is similar to adoption except that it takes place earlier than adoption.

According to the American Society of Reproductive Medicine's (ASRM) Ethics Committee, it is ethically acceptable for a programme to treat an embryo as abandoned if five years have passed since the last contact with a couple.[10] However, it is not permissible to donate these embryos to other couples or use them for research without prior consent of the couple.

Another controversial issue under debate is the use of embryos in research. This debate generally revolves around the moral status of the embryo.[11] Those who consider the embryo as a human, feel that it should be accorded the rights and respect that every human deserves. In the other point of view, the embryo is seen as deserving respect as a potential human being, but it is not entitled to receive the same respect as that of a human being. According to this point of view, "The embryo lacks the criteria traditionally equated with human status."[12] The ASRM holds to the

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6 Edwards G Hughes, Mita Giacomini, Funding IVF Treatment for persistent sub fertility: the pain and the politics: Fertility and Sterility Vol 76, No 3, September, 2001

7 Lori B Andrews, Ethical Considerations in Invitro Fertilization and Embryo Transfer, C.L.R. Bawrat and I.D Cooke (eds.), Donor Insemination, Cambridge Univ Press, 1993, USA

8 ibid

9 Melanie Blum, Embryos and New Reproductive Technologies, http://www.surrogacy.com/legals/embryotech.html

10 Disposition Of Abandoned Embryos: http://www.asrm.org/Media/Ethics/abandon.html

11 Donating Spare Embryos for Embryonic stem Cell Research: ASRM Ethics Committee Report: Fertility and Sterility Vol 78, No 5, November, 2002.

12 Donating Spare Embryos for Embryonic stem Cell Research: ASRM Ethics Committee Report: Fertility and Sterility Vol 78, No 5, November, 2002, Page 958

second view and considers embryo research ethical if it is conducted in ways that accords the embryo respect.[13]

However, in the Indian context, the utterly unregulated and unmonitored situation paves the way for large-scale sale of spare embryos, which is considered to be unethical.

Surrogacy

Surrogacy, i.e. carrying a pregnancy for someone else, raises many ethical issues like, should surrogates be compensated, is it right for the child to know the truth about his/her birth, etc. More and more women are now agreeing to be surrogates for their families and friends. The past 2 years have seen a 150 per cent rise in surrogacy cases in India.[14] Commercial surrogacy is also becoming common, with surrogates charging between Rs. 1 to 3 lakhs.[15] Commercial surrogacy can also lead to the exploitation of women from lower socio economic background.

Surrogate motherhood has a deep emotional impact on the surrogate mother as well as the prospective parents. The mother may be unable to part with the child after carrying it for nine months, whether or not the child is genetically related to her. This often leads to emotional anguish and long custody battles.

In most of these cases, the issue of donor anonymity comes up. While donor anonymity protects the privacy of donors and recipients, it often undermines the interest of the offspring born cut of this process.

Regulation of ART clinics and practices

ARTs represent just a fraction of infertility treatment, but in the decade since they were established in India, IVF clinics have sprouted up all over the country. As there is no national registry for these clinics, it is difficult to arrive at figures on the number of such clinics.[16] Thus, difficult questions need to be answered before ARTs can be deemed to be safely regulated in India. Indeed, the West Bengal State Director of Medical Education, C. R. Maity in 2003 stated, "Artificial reproductive clinics in the city were registered as ordinary clinics till recently, which is why the government knows so little about them. We admit to the glaring lapses in the system."[17]

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13 ibid

14 Vandana Majumdar, No kidding: Rent a womb, go the family way, Hindustan Times, July 10, 2004

15 ibid

16 ICMR, National Guidelines for Accreditation, Supervision and Regulation of ART clinics in India. 2005

17 Sujoy Dhar : Inter Press Service, Kolkata June 5, 2003, http://www.aegis.com/news/ips/2003/IP030606.html

Thus, in a society that places such a premium on fertility, treatments offered by IVF clinics, general practitioners, and unlicensed specialists flourish in cities and small towns. Meanwhile, the government does nothing to monitor the quality of treatment provided by infertility clinics - or any other health service. "A few states have passed laws requiring nursing homes to register themselves," says Dr. Jesani, "But that does not mean they are monitored."[18]

In May 1998, Drs Sumeet and Sumita Sofat, who run the Sofat Infertility and Women Care Centre, Ludhiana, announced that they had helped 61-year-old Karanjit Kaur, conceive. The high-tech pregnancy was said to have been made possible with the help of various hormones and in-vitro fertilisation. The Sofats stated that a urine pregnancy test was positive after two weeks and an ultrasound scan showed a live foetus at six weeks. However, when Karanjit Kaur returned to her village in Ferozepur after the IVF, she developed complications, and eventually had to undergo a dilatation and curettage to remove an incomplete abortion. Strangely, a histopathology test did not confirm pregnancy.

Source: Rajinder S Taggar and Ramninder Bhatia, Indian Express, August 17, 1998

These are not isolated events, but indicate a larger trend that makes it mandatory for us to question the kind of laws, guidelines, and regulations that exist around ARTs in India. A recent incident in Kolkata also points towards the risk of HIV–AIDS in having a baby through semen donation. A 35-year-old woman in the eastern Indian metropolis of Kolkata had contracted HIV from artificial insemination, which shocked health officials in the country.[19] Transmission of HIV from a donor's sperm occurs when he is not screened properly. The incubation period of HIV also plays an important role. If a donor is tested today, the result might not be positive. But six months later, it might. So, insemination should not be done within six months of

Crackdown on infertility clinics

With complaint after complaint pouring in - around 50 by now- from couples duped by the mushrooming infertility clinics, the state government decided to crack down. On the block are some 20 infertility clinics, all located in and around the city, which will be "sealed for good" by early 2003. A team of doctors, considered to be experts in the relevant field, under the aegis of the Indian Council of Medical Research, will visit them, along with a police team, to identify and lock them up.

"The government is determined to wipe out these blots," said State Director of Health Services, Prabhakar Chatterjee. Admitting that the government had no idea while granting licenses about how the clinics would turn out to be, he said that the government - with the complaints acting as "eye-openers" - had made up its mind to "do everything possible against them".

Source: Bappa Majumdar, Telegraph 2/12/03
http://www.telegraphindia.com/1021203/asp/calcutta/story_1443096.asp

18 Srinivasan Sandhya, Surrogacy Comes Out of the Closet, Sunday Times of India. Review. July 6, 1997.

19 Sujoy Dhar: Inter Press Service, Kolkata June 5, 2003,

donation.[20] Experts say that tests including the Elisa, Polymerase Chain Reaction (PCR) and P-24 antigen tests should be done to eliminate the possibility of HIV infection before opting for artificial insemination.[21] These new technologies require prior medical examination and continuous monitoring, as well as back–up systems to deal with severe side effects. In India, such conditions are hardly fulfilled due to poor health infrastructure and abysmal heath services, alongside ingrained gender biases. But this has not stopped the sprawling of "high-tech" infertility clinics and their prosperity with an average of 300 patients coming every month. A pilot study done by Sama, in Kolkata with gynecologists, brought out similar anxieties. The doctors interviewed pointed out that lack of formal guidelines has led to spurious use of these methods; "There is no sperm bank in Kolkata, frozen sperms come from outside. The companies claim that regular screening is done." However, the doctors interviewed felt that the lack of a monitoring system makes it hard to ascertain these claims.

These instances highlight the need for a comprehensive and effective legislation to regulate and monitor the use of these technologies and to protect and safeguard the interests of the persons accessing these services.

In a situation, where many of these technologies are yet to be proven satisfactory for use on patients, there is clearly a need for guidelines and regulations.

To check many of the unethical practices and regulate the proliferation of unsafe techniques, many countries[22] across the world have developed legislations and guidelines on the practice of ARTs. In India though, there has been an unprecedented and unregulated growth of ART market over the years. Since the late 80s/early 90s, there has been no attempt by the government to either systematically monitor or regulate the industry. The only document that mentioned ARTs was the 'Ethical Guidelines for the Biomedical Research on Human Subjects' that ICMR published in 2000. This document contained a chapter suggesting guidelines for the practice of ARTs. Subsequently in 2002, ICMR released another draft guideline specifically on Accreditation, Supervision & Regulation of ART Clinics in India, which was released as a published document in 2005.

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20 Jyotsna Agnihotri Gupta, New Reproductive Technologies, Women's Health and Autonomy- Freedom or Dependency? 2000, Sage Publications.

21 Sujoy Dhar, Inter Press Service, June 5, 2003

22 Austria, Australia, Brazil, Canada, Czech Republic, Denmark, France, Germany, Greece, Hungary, Iceland, Israel, Italy, Japan, Korea, Mexico, Netherlands, Norway, Saudi Arabia, Singapore, South Africa, Spain, Sweden, Switzerland, Taiwan, Turkey have legislations, guidelines formulated by scientific societies exist in Finland, Poland, Portugal and the USA. Argentina, Egypt and UK have both guidelines and legislation, cited in National Guidelines for Accreditation, Supervision & Regulation of ART Clinics in India, 2005

This was indeed an important move towards monitoring and regulation of the ART industry in the country. Though we believe ICMR has attempted to look into the issue of ARTs to a certain extent, it apparently has a poor understanding of the social and ethical implications of the technologies. In this context, we found it crucial to review the guidelines recommended by ICMR. However, this critique that we have put forth, is an attempt to positively add to the guidelines, so that it contributes in making the document more holistic and comprehensive. The guiding principle is that when these guidelines are implemented, they should address equally the interests of all sections concerned, rather than being lop-sided in their approach. The attempt is not only to critique the document but also to understand its implications in the larger social context.

Part 2: Critique of the ICMR guidelines

Introduction

In the course of our research we came across several discrepancies between the ICMR guidelines and actual practice. Some of these issues are discussed under the following sections:

Sterilisation and ARTs

The guidelines say under 1.1.1 that ARTs provide an alternative to reversal of sterilisation. "Infertility, consequent to use of terminal methods of contraception under the Family Planning Programme, may sometimes need to be reversed for personal reasons such as having lost a child/children born prior to sterilisation."

In our interview, one of the senior scientists from NIRR also emphasised that, "Family planning was the main concern and there were many people coming for reversal of sterilisation to conceive a child. It was felt that IVF would be the better option than recanalisation. That is the logic behind why the Institute started using these technologies. However, it happens in extreme tragic conditions. We had one lady who came for IVF when her 13 year old child died and she had already undergone tubectomy."

This statement is endorsed in a different way by a provider from Mumbai who stated, "The cost of the treatment becomes expensive because of the drugs, which are imported. The government can play an active role in bringing down the cost of the treatment. Many people lost their children during Tsunami and most of them had undergone sterilisation due to government's fierce sterilisation drive. The government now, as part of their Family Planning Programme, should ensure that these people can also have a child through these techniques."

This makes it obvious that ARTs can be manipulated as another instrument in the hands of the population controllers to further their larger objective.

Infertility as a disease

The guidelines construct infertility as a disease and the infertile as patients, which makes medical intervention not only a necessity but also the only way to deal with infertility. It also leaves no stone unturned to glorify treatment and medicalise infertility. The guidelines also say (1.6.4) that, "IVF is a therapeutic option of reproductive medicine with the highest yield per attempt, coming close on many occasions to that achieved by fertile couples conceiving naturally."

What ICMR means by therapeutic option is unclear. The Oxford English Dictionary gives two meanings of the word therapeutic. First it means "curing of a disease". Its second meaning is "contributing to the relief". The sense in which ICMR has used the word therapeutic, and the basis on which it claims that IVF has the "highest yield" per attempt, coming close to conceiving naturally, are both not known. However, it is a well-known fact that the take home baby rate with IVF is only between 20 to 30 per cent. Such rhetoric not only misleads people, but also leads to further invasion of women's bodies by the medical establishment.

Eligibility

ICMR has set some eligibility criteria for women who wish to use ARTs. The criteria are essentially based on a moral perspective that it attempts to impose on the women using of these technologies. Though the document makes a passing remark about single women in one of the sections (3.5.2), there is no reference to it in the consent forms.

Lesbian women, gay men, single women and their concerns are inconspicuous in the whole document. This is all the more disturbing as the ICMR guidelines, 2000, had a section on the use of ARTs by single women, lesbian and gay couples, stating that, "There would be no bar to the use of ART techniques by single unmarried women or a lesbian couple or a gay couple, who wish to have a child and no ART clinic may refuse to offer its services to the above, provided other criteria mentioned in this document are satisfied. The child thus born will have all the legal rights on the woman or the man."[23] Strangely, this finds no place in the present document. To be precise, the guidelines revolve around the heterosexual and monogamous married couple.

Language

The language used in the ICMR document is one of its central problems and reflects the ICMR's poor understanding of various issues.

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23 2002 National Guidelines for Accreditation, Supervision and Regulation of ART clinics in India.

Referring to the persons who seek services at these clinics, the document primarily uses terms like husband and wife with an occasional token the term partner. The guidelines in spirit operate within a hetero-normative framework and the women undergoing these procedures are assumed largely to be married and in heterosexual relationships.

The guidelines at another point make the celebration of motherhood within marriage as the only context for the provision of artificial insemination using a donated sperm (AID). Section 3.16.4 reads, "There is no legal bar on an unmarried woman going for AID. A child born to a single woman through AID would be deemed to be legitimate. However, AID should normally be performed only on a married woman and that, too, with the written consent of her husband, as a two-parent family would be always better for the child than a single parent one, and the child's interests must outweigh all other interests."

Ironically, the title of this provision is "Rights of an unmarried woman to AID". It makes clear, first, that a woman's desire to have a child is legitimate only within a marriage, and more significantly, only if it is supplemented by the written consent of the husband. In other words, not only must the husband consent, but the consent should be capable of being proven in a court of law. Secondly, it imagines that a "two-parent family" would always be better for the child than a single parent family. [24]

In a similar way, another section 3.16.2 mentions, "ART used for married woman with the consent of the husband does not amount to adultery on part of the wife or the donor. AID without the husband's consent can, however, be a ground for divorce or judicial separation."

This reinforces male ownership of the woman's reproduction and sexuality as is articulated in the law against adultery in the Indian Penal Code (IPC), which criminalises the act of sex with a married woman, except with the consent of her husband. Adultery is an offence under Section 497 of the IPC, which perceives a consensual sexual union between a man, married or unmarried, and a married woman without the consent or connivance of her husband as an offence of adultery. The law relating to adultery is not only based on the husband's "right" to fidelity of his wife but also treats a wife merely as the property of her husband. Such a gender discriminatory and proprietary oriented law of adultery is contrary to the spirit of equality guaranteed under the Constitution of India. The ICMR guidelines are also premised on a similar line of thought, which [25] reiterates stereotypes and strengthens the roots of unequal gender relations.

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24 In other words, Sama 2006 (unpublished document)

25 Ibid

"Legitimacy" of children born through ARTs

The ICMR guidelines state: "A child born through ARTs shall be presumed to be the legitimate child of the couple, born within wedlock, with the consent of both the spouses, and with all the attendant rights of parentage, support and inheritance."[26] This definition of legitimacy is premised on the assumption that only children born within wedlock are legitimate. Such an assumption is problematic firstly, because a child should not be accorded legitimacy based on her/his birth within or outside "wedlock". This essentially violates the rights of a child to live a life of dignity, irrespective of whether he/she is born within the institution of marriage or otherwise. Moreover, it is also an exclusion of single women and men and same sex couples from using ARTs.

Supervising and regulating the practice of ARTs

According to the Director General (DG) of ICMR, "There are no guidelines for the practice of ART, accreditation of infertility clinics and supervision of their performance in India. This document aims to fulfill this lacuna and provide a means of maintaining a national registry of ART clinics in India."[27] Though the DG claims that these guidelines are a step forward in the process of accreditation, there seems to be no systematic engagement towards the implementation of this process. There is a mention of the responsibilities and composition of the National Advisory Committee and the State Appropriate Authority. The scope and powers of these committees in monitoring and regulation of implementation is not very clear or comprehensive. Furthermore, the composition of the State Accreditation Authority finds no place in the document.

In this context, several issues require clarity, some of which are listed below:

- Is the State Accreditation Authority only responsible for issuing and revoking licenses?
- What should be the qualifications for appointment of its members?
- What executive power does it have?
- If it has executive powers for inspection of ART clinics etc., what will be the modus operandi?[28]

It is not known at present, whether such registration or accreditation has begun and, if it has, how ICMR plans to make the women aware of such registration. Further, which bodies or authorities may provide accreditation to the clinics? How will ICMR ensure that the women only go to authorised or accredited clinics?

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26 ICMR Guidelines 3.16.1, pg 74

27 Ibid, Preface pp xiv

28 Saheli Women's Resource Centre, ICMR Draft Guidelines for Assisted Reproductive Technologies: A Critique and Some Recommendations, November 2002

Physical requirements and code of practice

The document speaks in detail about the physical requirements of the clinic. It refers to categories of infertility care units, which includes primary level (1A), primary level (1B), secondary level and tertiary level.[29]

Section 2.5.1 states, "level 1A clinics will ...maintain records, these records will be liable to inspection by an appropriate review committee." At the same time, it also states that a level 1A clinic will not require accreditation under these guidelines. If the level 1A clinics are not accredited or officially recognised, how will the committee review the records of these clinics and ensure exactly what services these are providing?

Our observations proved quite contrary to what the guidelines say, as we did not find any such categorisation during our research. Referrals to clinics were largely given by friends and relatives who had used the IVF services at specific clinics. In such circumstances, it is not possible to ensure that the person(s) accessing these services in accordance with his/her requirements, will go to a particular level of clinic nor, with the practice largely being private, be turned away or referred to other clinics as appropriate.

Counselling

The guidelines state that counselling is a crucial component in the treatment process, and would ensure that the people accessing these techniques are thoroughly informed of the procedures and also ensure consideration of other alternatives like adoption, before opting for ARTs. Section 1.5.4 claims that, "a person who has a degree in social sciences, psychology, life sciences or medicine and a good knowledge of the various causes of infertility and its social and gender implications" is qualified to occupy the position of a counselor.

The guidelines remain largely silent on the nature and content of counselling to be provided, with the only reference to specific content of counselling appearing in 1.5.4, "The counselor must invariably apprise the couple of the advantages of adoption as against resorting to ART involving a donor." In 3.2.6, there is a passing mention of supportive and therapeutic counselling without any further details.

However, our research revealed quite a dismal picture in this context. One of the providers we interviewed, maintained that it was difficult to orient counsellors on the technicalities of the procedure involved and another held that the women feel

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29 Ibid, section 2.5, pg 48

satisfied only when counseled by the doctor. Some other examples include the following:

- Two providers said special counselling is provided to patients who are going for donor sperms or donor eggs.
- Four said counselling is provided to patients to deal with stress related to infertility and also for going through these procedures as there is pressure on women to get pregnant in the first cycle only.
- One provider said counselling is provided in special cases, for example, when both the husband and wife have thalassaemia.
- One provider said counselling is provided only to certain patients who "are nervous, apprehensive and cannot decide to carry on the treatment" or "find it difficult to cope with failure."
- One provider said, "counselling is done to understand the patient's mindset and moderate treatment accordingly."

In the course of our interviews with women, we found that counselling was provided by the doctors themselves.

One of the women interviewed stated, "I don't know the name of the procedure. I have undergone a small operation and now I am on drugs prescribed by the doctors." This is a glaring lapse not only indicating inadequate counselling but also with regard to provision of information and informed consent.

It is important that a distinction be made between counselling and provision of information. Accepting counselling might not be mandatory but the provision of information by the ART clinic must be mandatory for the clinic along with supplementary counselling services.

The guidelines maintain that an andrologist, an embryologist, and a counselor can render their services to more than one clinic without compromising the quality of services in any one. But one can reasonably point out that such a scenario will not only intensify commercialisation of the professions but also compromise the quality, which may further risk the health of the women undergoing these procedures.

Adoption

Adoption has been advised only when the IVF fails: "Treatment for the unresponsive couples will then consist of counseling and an in-depth investigation leading to the use of ART, failing which, adoption may be the only alternative." This makes it quite evident that even ICMR considers adoption as a secondary option, to be considered

only if the ARTs fail, though ideally it should encourage the options of adoption or foster-parenthood. This further gives justification to the provider's emphasis on ARTs as a primary option and closes the door on alternate parenting.

Age

As regards the issue of minimum age of a woman using ARTs, section 3.14.1 states that, "For a woman between 20 and 30 years, two years of cohabitation/marriage without the use of a contraceptive, excepting in cases where the man is infertile or the woman cannot physiologically conceive. For a woman over 30 years, one year of cohabitation/marriage without use of contraceptives. Normally, no ART procedure shall be used on a woman below 20 years".[30] While this section of the guidelines articulates the minimum age for a woman using ARTs as 20 years, its stand on the maximum age is ambiguous.

As a provider from Mumbai said, "The age restrictions in the guidelines are also surprising. How could the guidelines restrict the age? This is up to the woman to decide when to have a child. If she is medically fit, who is the ICMR to say no? Even a post menopausal woman has a right to go for pregnancy."

In the case of women who have reached menopause, the guidelines (1.6.7.1) say, "the endometrium of menopausal women has the ability to respond to sex hormones and provide a receptive environment for implantation of an embryo." Though it maintains that they can undergo these techniques, the maximum age at which a woman can go for treatment is not mentioned. Moreover, the health implications of ARTs on menopausal women is not spelt out anywhere in the document. In our research, there was no consensus among providers on administering ARTs on menopausal women, and this has been highlighted in the findings chapter.

According to one of the providers, "ICMR, in its guidelines, has restricted the age for undergoing these techniques. I agree with the guidelines. There should be an age restriction. Only in exceptional conditions, we can extend the age; otherwise, it is strenuous for an elderly woman to bring up the child. Some doctors see no harm with the age of the woman exceeding 50. They publicise 'providing the techniques to a postmenopausal woman' as an achievement. I do not see this as an achievement. It is not advisable for a postmenopausal woman to go for IVF for her own health reasons."

Age of donors

ICMR also maintains a considerable degree of ambiguity in relation to "age and eligibility" of egg donors and sperm donors. In section 1.6.7.1, it says, "egg donors

30 Ibid, Section 3.14.1, Pg 71

should be healthy in the age group of 18-35."[31] In other sections (3.5.8 & 3.7.4), it says the age of oocyte donor "must not be less than 21 or more than 35 years." We feel that ICMR is maintaining this ambiguity over a crucial issue, which is likely to have implications on the egg donor's health, and this stand from a regulating and monitoring body is disappointing.

THIRUVANANTHAPURAM, MAY 4. Bhavani Amma, a 62-year-old woman past her menopause, has given birth to a male child through in-vitro fertilization (IVF) and embryo transfer (ET) method in a private infertility clinic (Samad IVF Hospital) in the city.

The baby, born on April 12, 2004 through a Caesarean section, weighed 1.35 kg. He had to be taken out at 34 weeks of gestation as the mother developed complications like gestational diabetes and hypertension. For the past two years, she had been undergoing specialised infertility treatment as she was past menopause; she had to undergo hormone replacement treatment to make her uterus receptive for pregnancy. A combination of IVF and embryo donation techniques was used to help the woman conceive. The sperm was taken from the sperm bank at the clinic, while for the ovum; an advertisement was placed seeking donors. The cost of the procedure was a little over Rs. 1 lakh..

Source: The Hindu, 05/05/04, http://www.hindu.com/2004/05/05/stories/2004050508360400.htm

ICMR also says that to be a surrogate a woman should not be over 45 years of age and should belong to the same generation as the woman desiring the surrogate, in case the surrogate is a relative. However, our research evidenced facts contradictory to this. Most of the advertisements for surrogacy maintain an ambiguity with respect to the age requirement. The providers also shared that there were women above 45 years coming for surrogacy.

Sperm and egg donation

The guidelines (3.5.13 and 3.5.14) say, "Use of sperm donated by a relative or a known friend of either the wife or the husband shall not be permitted." The same will be "true for oocyte donation." However, our interviews with the providers brought out different opinions about whether donors should be related or not. Most of the providers felt that in case of egg donors it is better to have related donors because of medical reasons, since "the woman has to be monitored for 15 days, and this requires a lot of commitment from the donor." However, there were concerns over the child being raised in the proximity of genetic parents, especially in case of sperm donor being a relative, since there can be claims of ownership of the child.

The above section in the document also mentions that, "Neither the clinic, nor the couple shall have the right to know the donor's identity and address." In this context,

31 Ibid

one of the providers said, "Ninety-five per cent get their own donors... and in case there is a problem, we have mediators who arrange donors." The crucial question here is how does ICMR monitor the whole process of sperm and egg donation and concerns of confidentiality. ICMR says that if semen banks are set up by ART clinics, they must operate as separate identities. Even if semen banks operate as a separate identity, covert dealings between the banks and the ART clinics cannot be ruled out.

Ethical and legal concerns

One of the contentious issues in this section is the cryopreservation of embryos. The document says (1.6.8.2), "As up to a maximum of only three embryos are allowed for transfer.... patients should be fully informed before the treatment cycle on the procedure of cryopreservation, the risks and particularly, what is to be done with their embryos if they do not use them. They should sign a consent form concerning the consent for embryo freezing as well as for the future use of embryos."

Though ICMR says only three embryos are to be transferred, how does it monitor the process? Even the woman undergoing these procedures has no means of knowing the exact number of embryos transferred, as the entire process is provider controlled. In this context, one of the providers we interviewed said, "We destroy the spare embryos. At other times we sell the embryos with the consent of the couple."

Section 3.11.2 says, "This consent shall not be required if the couple defaults in payment of maintenance charges after two reminders sent by registered post." Here it is vital for ICMR to state the charges for maintenance. We need to ask what is done in circumstances where the couple/person do not consent to use their spare embryos for other couples/person or research, but only because of lack of resources, they fail to make periodic payments.

ICMR says (1.6.11.3), "The sale or transfer of human embryos or any part thereof, or of gametes in any form and in any way - that is, directly or indirectly - to any party outside the country must be prohibited. ...Within the country, such embryos or gametes could be made available to bonafide researchers only as a gift, with both parties having no commercial transaction, interest or intent."

The concern here is how does ICMR monitor and ensure that there is no commercial transaction-taking place when there is such growing interest in embryonic stem cells. Given these circumstances, ICMR fails to propose how it plans to ensure that commercial arrangements do not come into play.

"The accreditation committee must approve all research that involves embryos created in vitro," says ICMR (3.2.9). It is problematic to say all research without specifying what kind of research and the maximum age of embryos used. These are debatable issues all over the world. The ethical guidelines need not set out priorities for research in this document. However, we need to have some protocols and stringent monitoring over the research on embryos.

In instances of surrogacy, there is no mention about the mode and amount of payment to be made. The document says that the ART clinic should not be involved in the monetary aspects. However, in our interview a woman shared her experience when she went to consult a doctor for some problem: "He told me that his clinic provides surrogates to clients who do not have children and that I too should engage in surrogacy. He explained to me that I would be doing a good deed by helping a childless couple have a child; *"Kisi ke ghar mein bachha nahin hua to aurat par ghar chodne ki naubat aati hai."* (sometimes when a woman cannot bear a child, the situation may be such that she is compelled/forced to leave home) He also suggested that I could get enough money to clear all our debts and loans." She later agreed to be surrogate and says that the doctor charged the couple Rs. 15 lakh and paid her two lakhs.

Section 3.10.7 of ICMR says, "A prospective surrogate mother must be tested for HIV and shown to be seronegative for this virus just before embryo transfer. She must also provide a written certificate that...she and her husband have had no extramarital relationship in the last six months."

This impinges on the sexual life of a woman who would be a surrogate. Again it attempts to rule out the inclusion of single women from surrogacy. Also, there seems to be an assumption by ICMR that HIV can be acquired only through "extramarital"relationship. Asking for a certificate not only reflects a narrow and stigmatising attitude towards HIV as a disease but also encroaches on the sexual lives of the individuals.

Section 3.5.4 also mentions that, "....An oocyte donor cannot act as a surrogate mother for the couple to whom the oocyte is being donated." ICMR as a scientific body cannot seems to be unable to move away from the whole discourse of motherhood - because here the surrogate will be both the genetic and the gestational mother - or is this just to protect the legal rights of the intended parents?

Sex-selection through PGD

Though sections 3.5.9 and 3.5.10 mention that ART clinics are not to offer sex-selection through PGD or other wise, there is no surety that the providers are not doing sex-selection.

During our literature review we came across a book on infertility 'How to Have a Baby: Overcoming Infertility' by Dr Malpani and Dr Malpani, which says, "If we allow people to choose when to have babies; how many to; and even to terminate pregnancies if they inadvertently get pregnant, then why not allow them to select the sex of the child, if its possible?"

"We should allow patients freedom to choose for themselves - medical technology should empower them with choices they can make for themselves! A common criticism against PGD for sex-selection is that it will cause unbalanced sex-ratio. In reality, PGD will allow couples to balance the sex-ratio in their families, rather than unbalance it! For example, take a couple with a baby girl who want to have a second baby. If they leave things up to chance, half of them will have a second baby girl, causing unbalanced intra family sex-ratios! PGD will allow them to make, if they have a balanced sex-ratio in their family, if they so desire. Seen in this light, PGD is perhaps the ultimate form of family planning there is!"

In a situation where the doctors believe that sex-selection through PGD is the ultimate way of balancing the family sex-ratio, the potential for misuse of technology to wipe out the girl child should be a matter of concern. The PCPNDT Act has failed to regulate sex-selective abortion and screening through PGD will make it easier for unethical practitioners.

Section 3.5.13 and 3.5.14 of the guidelines mention that, "The clinic and the couple have the right to have fullest possible information...on the donor such as height, weight, skin colour, educational qualification, profession family background." Some of the criteria listed might sound unproblematic, given a scenario where the couples would want to have a child who looks similar to them, but other criteria like skin colour, profession and family background actually may lead to promotion of eugenics or even promote the view that genes could promote certain socially desirable traits. In all probability, people would only want fair-skinned babies (most popular in India) from a high caste and class background and hence the perpetuation of eugenics. It is not clear whether ICMR has devised any way of dealing with such eugenic selection.

There are various ethical concerns related to the screening of the embryos. The main purpose of sex screening was to help couples avoid x linked diseases to be passed on

to their children. One of the main concerns is sex-selection for non-medical reasons since Indian society is largely patriarchal and the preference to have a male child can be traced back to centuries. The practice of determining the sex of the foetus and aborting it in the case of female child is quite common. Thus, introducing a technique that makes sex-selection before implantation possible in India provides the potential for its misuse.

Informed consent

ICMR emphasises the need to get informed consent of the couples, especially women, before embarking on the ART procedures and that treatment would be administered only after obtaining a written consent. It has devised a standard consent form for couples, with separate forms each for Artificial Insemination with Husband's Semen, Artificial Insemination with Donor Semen, consent for freezing of embryos, consent for the procedure of PESA[32] and TESA[33] for ICSI, consent for oocyte retrieval and embryo transfer, consent for the donor of eggs, consent for the donor of sperms and a form to consent for surrogacy.

A minute scrutiny not only reveals several gaps between official rhetoric and ground realities, but also certain contradictions and inconsistencies inherent in the language used. There is too much emphasis on an optimistic scenario. The forms were not developed on the social, cultural and religious contexts, which may not allow free and voluntary choice. The language used in the consent forms which is similar to that used in the whole document seems quite problematic. It repeatedly uses expressions like husband and wife ignoring the possibility of other categories such as gays, lesbians and single women who might desire to make use of these techniques.

The vital purpose of the consent form is to ensure that women have ample knowledge of the procedures, along with the potential side effects and complications, success rates etc. that they are undergoing for treating infertility.

Though the guidelines claim to make the consent forms available in English and the local language (3.3.11), our study did not provide any evidence of the availability of the consent forms in the local language. One of the participants who had used the method of ICSI in an ART clinic in Hyderabad revealed, "Yes, we signed the informed consent form, but it was in English. As we do not understand English, the doctor verbally translated the contents in Telugu and we signed it."

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32 Percutaneous Epididymal Sperm Aspiration

33 Testicular Sperm Aspiration

The pertinent question in such instances is how one ensures whether the doctor has provided adequate and necessary information regarding the procedure involved? In this case, it was ICSI, which holds a high risk of genetic abnormality in the offspring. In the same instance, we interviewed the doctor who believed there was no risk to the progeny born of this technique, which made it quite clear that no such specific information was provided to the women undertaking these techniques.

On reviewing the sample consent forms we found that the potential risks of ovarian stimulation, oocyte collection, multiple pregnancies, ectopic pregnancies and miscarriage related to IUI and IVF were not mentioned. Though there is a separate consent form for PESA and TESA for ICSI, there is no mention of the risk of genetic abnormality inherent in the technique. How do participants take informed consent decisions when information on efficacy, long-term safety and psycho-social implications are not adequate?

In Kerala 2002, Anita Jayadevan approached an infertility clinic for assisted reproduction. An embryo was transferred after an ICSI. Two months hence Anita developed acute abdominal pain and was operated on in another clinic/hospital but her pregnancy had to be terminated and the couple suspecting foul play sent the foetus for DNA testing and found out that Anita had actually been implanted with another women's eggs. She has filed damages for RS 20 lakhs Rs. Dr K.K Gopinath responded saying that an oral consent had been obtained to use a foreign ova. M.R Chandran, Director of Medical Education says that a comprehensive law is yet to be in place to be able to check such unethical practices. Anita's case is being heard in Tirur sub court Mallapuram.

Source: John Mary, The Telegraph, Kolkata 2/2/04

The guideline (3.5.22) says that, "The consent on the consent form must be a true consent witnessed by a person who is in no way associated with the clinic." Though this provision seems to be quite sound and reliable, the guideline contradicts itself, as the consent forms demand signature of a witness from the clinic. Moreover, in a country with dwindling literacy rates, how does one ensure that the women read and comprehend the consent forms before undertaking any ART procedures? This context makes the presence of a witness outside the clinic a priority.

The consent form for surrogacy demands the consent of the woman's husband, excluding the possibility of a single woman to be a surrogate. The other issue is that, "AID without a husband's consent can be a ground for divorce or judicial separation." This again reiterates that a woman has no control over her own body and she requires authorisation from her husband for every move.

Provider's perception on ICMR guidelines

Though ICMR has devised guidelines which ostensibly aim to "regulate and supervise" the clinics providing services of ARTs, it is crucial to look into the perception of providers on the guidelines. Some of the doctors in our study pointed out the following:

"ICMR guidelines are impractical. The guidelines are not legally binding."

"Who is ICMR to decide on the age? Even a postmenopausal woman can go for IVF."

"How are you going to ensure that the donor of sperm is not a relative?"

"We cannot have separate registration for sperm bank; we have our own sperm bank which makes it easily accessible."

"ICMR says that the clinic should have all facilities but it is not possible to have so many rooms. Imagine in a city like Mumbai, how can we have so much space?"

"Using unknown, unrelated donor is not practical and what is the need for so many consent forms. It took five years to publish the guidelines, and it may take another 50 years to implement it. We follow the American guidelines."

Conclusion

ARTs, as we have seen, throw up a wide range of issues - medical, social and ethical - and have already begun to change all existing perceptions of procreation. Since they are also hugely profitable, they have a great potential for misuse. Considering all these qualifications, it is only natural to expect some regulatory mechanisms that can restrict their boundaries and safeguard rights and interests of individuals who could be vulnerable. However, on a look back at regulations, a number of questions immediately come up. Are regulations only a few well written, politically correct principles to remain on paper? Who frames the guidelines, from what motivation and perspective? How effectively are they enforced, monitored or amended from time to time? True, these, and many more critical questions have cast a dark shadow of cynicism on regulation. But can we really afford to do away with regulations altogether? When it comes to regulatory mechanisms for ARTs, it is obvious that the drafting body, ICMR, is yet to come to terms with the range of challenges that ARTs have brought to the fore. What is of greater concern is the limitation of understanding that the ICMR has shown on issues concerning women. A substantial overall of the guidelines is of imminent need to make providers more accountable to the users and the society; and address the ethical issues that are emerging out of unrestrained application of the technologies, such as sperm and gamete donation, sex-selection, surrogacy and cloning. In a situation where the global capital is shaping policies and trade agreements, regulatory mechanisms become even more crucial.

CHAPTER 6

Responses from Progressive Movements

Though Assisted Reproductive Technologies have made inroads in India from the early 1980s, it is interesting to note that there has not been any systematic engagement on the part of the ongoing movements in the country regarding this issue. While women's movements have been vocal about their concern with contraceptives, their examination of technological interventions has been restricted to technologies for sex-selection. Personal communication with women's rights activists, health activists, disability rights activists and sexual rights activists, and those involved in the ethics movement[1] have brought in a wide range of factors which has led to the sidelining of this issue.

The activists[2] from the women's movement reiterated that, (in the words of one feminist), "ARTs never became a women's issue in the way hazardous contraceptives and sex-selection had, because whereas coercive population policies and hazardous contraceptives affect almost 90 per cent of the population, only about 10 per cent gets affected by infertility and even lesser by these techniques." Moreover, some women's groups perceive women who are seeking ARTs as playing a voluntary role vis-à-vis women who are forced to use hazardous contraceptives without consent or information. Some of the main reasons or justifications for a lesser degree of involvement with ARTs that came up in the course of our discussion include the following:

1. "Prevalence of the technologies were not wide"
2. "Concentrated in the urban sector"
3. "Primarily in the private sector"
4. "Given its epidemiology only 5 per cent people suffer from the problem of infertility"

Some activists also stated that ARTs never became a campaign issue because they were provided by private clinics and were away from the public eye. Therefore,

1 The fact that these are individual accounts, the perceptions do not necessarily reflect the official position of the movement but the individual's own understanding, dilemma and concerns.

2 No names have been mentioned to maintain anonymity

information regarding them was scattered. Thus, there were only abstract philosophical discussions on the issue but no concrete steps were taken.

The women's movement has been well versed and efficient in conversing in the language of violence, discrimination and victim-hood. However, issues around conceptive technologies have been seen more in terms of interaction between the private practitioner and the patients. It has been difficult apparently to find a victim in this scenario, which is crafted in the language of choice between an individual person and her doctor. Thus, in the words of one activist, "We have been successful in evolving groups and raising political consciousness around deserted women, widows, but not childless women. However, infertility was identified as a reason for desertion, divorce, harassment and battering." Thus, besides various factors from within the movement, certain external factors (read, market forces) have also played an important role in marginalising the issues of ARTs, in the women's movement. Primary among these is the rhetoric of choice that is used to justify and promote the use of ARTs. Most of the activists confessed to grappling with this issue of choice, freedom and right. In the words of one, "Even all our movements are thriving to increase choice by fighting discrimination. Choice in which context is important to decipher. Is choice framed as a consumer product? Is choice ethical? What kind of precedent does that choice set? Does it violate others' rights? Is the choice empowering? Does it exploit or oppress anybody else?"

Activists associated with the disability movement generally explained their non-engagement with ARTs by stating that in India the movement is concerned more with issues of survival and is still struggling to gain equal access to facilities in education, jobs and political participation. Therefore, they explain, the disability movement has not yet reached a state where it is able to articulate issues about genetic selection and screening.

Those associated with the ethics movement in India also voiced a similar rationale for not taking up the cause of ARTs too seriously. One of them went as far as to say that although New Reproductive and Genetic Technologies (NRGTs) were a "minefield of ethical issues", they were still being neglected due to the belief that they were accessed by a very small, usually urban minority. Moreover, the rhetoric of choice again comes to function here and right and freedom are poised to counter ethics.

The sexual rights activists were also of the opinion that the movement is at a nascent stage of raising questions around marriage, and the need to have one's own biological child.

However, this is not to say that the issue of ARTs has not been addressed at all in Indian context. There are concerns regarding these technologies that have been raised, albeit minimally, by the autonomous women's movement. An important document in this regard has been 'We and our Fertility'[3] which looks into the entire range of reproductive technologies from the point of view that there is no fundamental difference between the two sets of technologies – contraceptive and conceptive and hence looks at it from a similar critical lens. Their commonality is based on the fact that both these sets of technologies intervene in the hormonal cycle either by promoting fertility or controlling it. Looking at these range of technologies as a continuum makes an important point of departure given the fact that in the Indian context even the growth and development of these technologies is programmatically linked with each other. There are also a number of other activists and academics who have engaged with the issue of ARTs, especially in the Indian context, in their writings.[4]

Rhetoric of choice

Concern of the women's movement and health movement with specific reference to ARTs emerged through individual voices from various movements. The main thrust has been to unearth the "politics behind the propagation of these technologies and the research that is carried out in this area with the aim to question the mainstream scientific view which looks at women's bodies as either reproducing mindlessly or not reproducing at all."[5] Also, an urgent need has been felt to demystify the concept of choice, which has worked to promote ARTs. Since these technologies are propagated within the parameter of choice it is critical to evaluate the concept of choice itself. For example, it is difficult to distinguish between latent choice and social choice shaped by family, market, and other agents. "Unless we draw this line, there is no limit to theoretical choice and everything, including sex selection, can be justified in the language of choice. What society does is to promote one variety of choice while silencing the range of options. The society closes the option that women can be happy without children or they can be happy with adopted children i.e. they cannot fathom that you can love a child who is not biologically yours." Thus, it is important to decipher the context in which choice is being promoted and offered. This alone can reveal the true nature of choice—whether it is liberating, exploitative, consumerist, welfarist etc.

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3 Chayanika, Swatija, Kamaxi, 'We and Our fertility – The Politics of Technological Intervention', 1999.

4 Malini Karkal, IVF in the Third World, Paper presented at Women, Procreation and Environment Conference, Rio de Janeiro, October, 1991; Lakshmi Lingam, Made in India: A Dossier on the New Reproductive Technologies, Tata Institute of Social Science, 1989.

5 Personal communication with Feminist Health Activists

Activists were also concerned about how the language of choice was being appropriated by the market and the policy makers. In this respect, the need was felt to either move beyond choice or be conscious about what was included within the parameters of choice. It is important to tackle what all is being promoted in the guise of choice. As one activist said, "Today we are asking for the desired sex of the child and tomorrow we will be asking for designer babies, thereby promoting eugenics. The language of choice also poses the danger of genetic screening of abnormalities and may lead to the elimination (read, abortion) of all that is considered to be (potentially) abnormal." One activist working on this issue said, "Genetics is threatening to a disability rights perspective, not just because it suggests that disabled people should be prevented from being born, but also because genetic reductionism challenges social modes of understanding of the social creation of disability, redefining disability in terms of biology and abnormality."

The lesbian, gay or queer movement is relatively new in India. This movement has questioned as well as problematised heteronormativity, on the grounds that it leads to the exclusion of everything that does not fit into the framework. In the words of one activist, "It's not just the biomedical category of infertility. We are also allowing certain kinds of couples to have children, and the basic unit of society is this particular family. This is what needs to be questioned in so many ways. And what are ARTs doing in this area. They are completely reinforcing this model of the family. And so there is a resistance from queers to this technology completely."

Essentialism

Another concern raised by the activists was the need to question the essentialism of biological parenthood. ARTs basically function on the assumption that every woman wants to have one's own child. Besides being grounded in it, they also further this assumption. This closes the door to other types of parentage, like adoption and also the reality of voluntary childlessness. Hence, they felt the need to construct positive role models for varied kinds of parentage. According to them, this deconstruction should also question the fundamental association of fertility with ideas of masculinity and womanhood.

Some of them also voiced a concern about using the language of reproductive rights. Accepting the reproductive rights framework and language was a cooption of the women's movement. What is important is to look at women's rights from the larger framework of rights, as one said, "If we reduce women's rights as equivalent to reproductive rights, we are reducing women's role only to being a reproductive being, denying her all other existential realities—of woman as a worker etc."

Emerging concerns

The commercialisation of the process of reproduction and its implications, especially on women, was a major concern raised by most activists. The focus of this concern is clearly articulated in this statement made by one of the activists, "Hundreds of companies have been formed, and more continue to be formed, to develop and promote technologies whose "benefits" are still questionable to a large extent. There are enough examples where the marketing of certain specific fertility drugs and misrepresentation of facts like success rates and health risks, solely for profit making, is clearly evident."

Moreover, the health risks and complications of these technologies are justified by the providers in terms of a cost/risk-benefit analysis. In response to this, a public health activist asserted that, "Cost-benefit analysis is invalid for health issues, because the inputs and outputs cannot be quantified. As a result, financial constraints determine public health priorities rather than epidemiological resources. This assumes that technology available is necessary, effective and safe." Also, as one activist said, "With increasing commercialisation and monetary benefits involved, in all probability, the womb will belong to women of so-called lower caste/class, and will open up newer avenues for their exploitation." Another one added that, "It is not just the lower caste and poor women any more. The business of egg donation has been growing rapidly even among the younger generation from middle and upper middle class. We have these classified advertisements searching for donors, placed in university campuses because college students are extremely desirable candidates as young people produce more eggs of a high quality."

There was also recognition of the fact that there exists a dilemma between philosophy and social reality, which is still unresolved. At the philosophical level we can say a complete no to all screening techniques, but one cannot ask for a complete ban on all screening techniques, as it is contextual. As mentioned by one activist, "Due to lack of support system, a woman may want to abort a disabled child. She cannot be denied this as in the absence of familial support, she has the sole responsibility of the child and may not be able to adequately fulfill it."

However, many activists interviewed felt that a complete ban on ARTs is not a solution to the problem. An activist stated that, "It is a myth that bans solve problems and that bans should be enacted to control a technology. Bans are not the most effective way of dealing with things, and often have unexpected repercussions and backlashes. Rather, efforts should be made to expose it as a technical solution to a social problem, and to work towards establishing formal and legally binding

regulations." Some women's groups[6] have worked towards this end by writing a critique to the ICMR guidelines regarding ARTs in India, which are not enforceable and in the words of one activist, "Read more like a document which is merely concerned about regulating a business, instead of providing an ethical framework."

The need for a public debate on the issue of ARTs was felt important given the fact there has not been much discussion and debate particularly on these issues. The sexuality movement, disability movement and ethics movement in the country also articulated the need for discussion, debates, thrashing up of ideas and strategies both within movements but also in public forums, because, "We tend to treat technology as magic, but if we understand it too well then we feel we won't be able to blindly trust it."

The fact that to initiate such debates it is also important to document the voices of those who have encountered these technologies or are providers of them, has prompted the present research study by Sama.

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6 Saheli Women's Resource Centre, ICMR Draft Guidelines for Assisted Reproductive Technologies: A Critique and Some Recommendations, November 2002 and Sama Resource Group for Women and Health, Critique of the ICMR Guidelines for Accreditation, Supervision & Regulation of ART Clinics in India, June 2006.

CHAPTER 7

Conclusion

Our attempt through the course of the study, as has already been stated earlier, was to be able to identify certain trends that have surrounded the proliferation of ARTs in India. We have documented these through the multiple voices of the providers of ARTs, and the women seeking these services. The key findings of the study have been summarised to enable an overview the implications of ARTs on women, in India.

The development and prolifieration of these technologies depend on the social imperative to have a biologically-related child. This social pressure may not be obvious, though women without children are blamed for their status, and ridiculed, abused and isolated socially, and often face desertion. There are many subtle ways in which women are indoctrinated to believe that motherhood is their destiny. If for any reason they are unable to become mothers, they must seek help to overcome the problem. Adoption is not seen as an option. The research indicated that both providers and women think that infertility is a disease for which treatment is required. At the same time, childlessness can be interpreted as being one's fate and god's will. This juxtaposing of medical terminology with social belief reveals itself even in the language of the providers. "When you are visiting a new doctor they always say that you will conceive if you use this technique, but as you go through one after the other treatment and nothing happens they say, "Ultimately it depends on God, we can only try our best." Providers play God, even as they attribute failure to another God.

The research also revealed an entire industry which cashes on women's vulnerability and the social pressure to have a biologically-related child at any cost. Thus information provided on diagnosis, the process of "treatment", success rates, side effects is distorted to portray these technologies in a good light. The clinics try to create an atmosphere by covering their walls with baby pictures, letters from couples praising the providers for bringing joy in their otherwise bleak lives. Each doctor's advertisement brochure proclaims him or her the "first" innovator[1] and portray

1 Aditya Bharadwaj, How some Indian baby makers are made: Media Narratives and Assisted Conception in India, Anthropology and Medicine, Vol.7, No. 1, 2000

these technologies as the answer to all problems. Though these images may support "patients" through the process, they also manipulate them to satisfy vested commercial interests. Media coverage of ARTs as medical breakthroughs, downplaying the associated risks and uncertainties, also adds to this picture, presenting a skewed reality. The glamourising of this industry is clearly an attempt to market it. But there is also a genuine belief system in play, which looks at these techniques as beneficial and miraculous. They also suggest that the cost of a child through ARTs is justified given the social importance of a child. This assumes the cost is justifiable regardless of one's financial background. The underlying assumption is that even expensive techniques becomes affordable when the end product (meaning a child) is held in high value. The research also revealed that in comparison to the high value attached, all physical and psychological risks and side effects are seen by the providers and couples as part of the bargain or a small price to pay. Added to this, the emphasis on success rates gives a picture that ARTs are the sole saviour of desperate women wanting to become mothers.

In this process of assistance the discrepancies in information provided to the women at least as revealed in this research, is far from the ideal. The information is generally provided in a piecemeal way and as and when a particular procedure failed. Thus rather than having a general idea of these techniques and possible information about them, what is provided can be called "directives" as to what to do next. The signing of informed consent forms also is not taken as mandatory in cases of IUI and wherever the consent forms are being signed it becomes more of a disclaimer on the part of the providers and the clinics to safeguard their own interest. The treatment which emerges is also that of a trial and error science and a never ending process which though has definite beginning but has no end to it. The increased pressure for infertility treatment comes in part from the unwillingness to fail to achieve pregnancy and also from the general awareness that infertility is no longer necessarily untreatable. It is in this framework that the spectrum of "choice" becomes quite limited as it becomes difficult to even conceive of a space where one can be outside the institution of marriage and family (meaning having child). Thus, the implications and the impact of these "treatment" are always weighted against that of having a baby. Although women face side effects of drugs, complication of procedure, go through numerous failed cycles and utter sense of frustration and desperation they do not think of "giving up". Why are women channeled, at such a cost to their bodies and themselves, into reproducing children for themselves and for others? Or, as is the case in many developing countries, why are women routed into not reproducing by state mandate or incentive programmes that promote more risky and harmful methods such as Norplant, Depo Provera and the vaccines? In many countries, why is it that women who want safe and adequate contraception have difficulty obtaining

it when religion and the State combine to legislate women's reproductive options? Why do these techniques reinforce the biomedical view that a woman's reproductive system is pathological and requires an enormous amount of intervention? Hundreds of companies have been formed, and more continued to be formed, to develop and promote technologies whose "benefits" are still questionable to a large extent. There are enough examples which make it amply evident that the marketing of certain specific fertility drugs is solely for profit making.

The implications of these technologies on women can only be seen in relation to the social context in which they operate. In doing so, the present research brings out the lived reality of women and speaks about both their negotiations and subjugation. In understanding the potential of these technologies it is important to understand the science and political economy behind these technologies, which not only assist birth of a child but attempt to "assist" life itself.

In the scenario of growing commercial interests and profit seeking in providing these techniques, the role of the State and regulatory bodies becomes important. The complex processes of gamete donation, embryo donation and surrogacy raise several issues of commercialisation, commodification, and psychological and physiological health implications to the women. Moreover, there are crucial issues related to supervision and regulation of ART clinics. Though the formulation of guidelines by ICMR has been a step towards this, these guidelines are not without limitations. As we have documented in the previous chapters, ICMR claims to have addressed these concerns and come out with guidelines for monitoring and supervising the clinics. There is no attempt to systematically bring out the implementation and strategies to monitor and supervise the ART clinics. Significant issues of age and eligibility are ambiguously dealt with in the guidelines. Moreover, we found considerable discrepancies in the simplistic assumptions of the guidelines and the ground reality. Such ethical guidelines are expected to go beyond technicalities and build effective safeguards so that the existing unequal power relationships between the providers of new technologies and those who access them is minimised. The guidelines should also take cognizance of the unequal gender relationships, and ensure that the rights of women using these technologies are not compromised in any manner.[2]

The women's movement had played a crucial role in systematically campaigning against hazardous contraceptives, coercive population policies and sex-selective abortion. However, there had not been systematic engagement of the movement with ARTs making our understanding of these technologies and their implication on

2 Saheli Women's Resource Centre, ICMR Draft Guidelines for Assisted Reproductive Technologies: A Critique and Some Recommendations, New Delhi, November, 2002.

women inadequate. And these implications, as we have already asserted throughout the document, move beyond the health risks that a woman undergoing ART procedures is vulnerable to. They reassert the norms of biological, heteronormative parenthood, to the exclusion of adoption and voluntary childlessness or even homosexual, or single parenthood. Moreover, the social stigma associated with infertility is taken a step further, and medicalised. Thus, to put it simply, ARTs raise various social, ethical, physiological and psychological implications, as well as potential drawbacks that must be addressed given the pace at which these technologies are invading the lives of women. This is necessary in order to enable a truly informed use of reproductive technologies.

Abbreviations

1. ARTs: Assisted Reproductive Technologies
2. AI: Artificial Insemination
3. AID: Artificial Insemination by donor
4. AIH: Artificial Insemination by husband
5. ASRM: American Society of Reproductive Medicine
6. FDA: Food and Drug Administration
7. GATS: General Agreement on Trade and Services
8. GIFT: Gamete Intra-Fallopian Transfer
9. ICSI: Intra-Cytoplasmic Sperm Injection
10. ICMR: Indian Council of Medical Research
11. IUI: Intra Uterine Insemination
12. HFEA: Human Fertilisation and Embryology Act
13. HMG: Human Menopausal Gonadotrophin
14. IVF: *in vitro* Fertilisation
15. IVF-ET: *in vitro* Fertilisation and Embryo Transfer
16. MCI: Medical Council of India
17. MOHFW: Ministry of Health and Family Welfare
18. NCAER: National Council of Applied Economic Research
19. NIRR: National Institute for Research in Reproduction
20. NRTs: New Reproductive Technologies
21. NRGTs: New Reproductive and Genetic Technologies
22. OGTT test: Oral Glucose Tolerance Test
23. OHSS: Ovarian Hyper Stimulation Syndrome
24. PCOD: Poly Cystic Ovarian Disease
25. PESA: Percutaneous Epididymal Sperm Aspiration
26. PGD: Pre implantation Genetic Diagnosis
27. TESA / TESE: Testicular Sperm Aspiration/ Extraction
28. TET: Tubal Embryo Transfer
29. TUDOR: Trans Vaginal Ultrasound Directed Oocyte Recovery
30. WHO: World Health Organisation
31. WTO: World Trade Organisation
32. ZIFT: Zygote Intra-Fallopian Transfer

Glossary

1. **Amenorrhea:** Absence of menstruation.
2. **Andrology:** Science of diseases of males, including infertility, spermatogenesis and sexual dysfunction.
3. **Anovulation:** Total absence of ovulation, menses may still occur - see amenorrhea.
4. **Artificial Insemination (AI):** Artificial Insemination is the procedure of transferring semen into the reproductive system of a woman. This technique comprises of artificial insemination with husband's (AIH) or with donor sperm (AID).
5. **Assisted Hatching:** Assisted hatching allows easier release of the embryo from its shell (zona pellucida) helping implantation and increasing the pregnancy rate.
6. **Assisted Reproductive Technologies (ARTs):** Any medical technique that attempts to obtain a pregnancy by means other than by coitus is defined as ART. In other words, these techniques manipulate the sperm and oocyte outside the body, and the gametes or embryos are transferred into the uterus.
7. **Ectopic Pregnancies:** An ectopic pregnancy is one in which the foetus develops outside the uterus- in the fallopian tubes, the cervical canal, or the pelvic or abdominal cavity.
8. **Embryo:** Embryo is defined as the fertilised ovum that has begun cellular division and continued development upto the blastocyst stage till the end of eight weeks.
9. **Embryo Cryopreservation:** Procedure in which embryos are preserved by freezing
10. **Embryo Transfer/Implantation/Transplant etc:** The transfer of an embryo from an *in vitro* culture into the uterus.
11. **Endometrium:** The mucous membrane lining the uterus, which becomes progressively thicker and more grandular and has an increased blood supply in the latter part of the menstrual cycle.
12. **Endometriosis:** Presence of endometrial tissue in abnormal locations
13. **Estrogen:** Hormone produced in the ovaries. It controls the development of the female sex characteristics and the reproductive system.
14. **Foetal Reduction:** Foetal reduction is an invasive/interventional process by which a higher order multiple pregnancy is reduced to a single or twin pregnancy in order to improve the perinatal outcome.
15. **Gametes:** Is a mature sex cell: the ovum of the female or the spermatozoon of the male.

16. **Gamete Donation:** Gamete donation is a process by which a person voluntarily offers his or her gametes for the process of procreation.
17. **GIFT (Gamete Intra-Fallopian Transfer):** Gamete Intra-Fallopian Transfer is the placement of ova and sperm in the fallopian tube(s) to effect fertilisation.
18. **Gonadotrophin:** Is any of the several hormones synthesised and released on the pituitary gland that acts on testes or ovaries to promote production of sex hormones and sperm or ova
19. **Hot Flashes:** Is a symptom usually related to menopause where the skin especially on the head and neck becomes red and warm (flushed) perspiration maybe profuse.
20. **Human Chorionic Gonadotrphin (HCG):** is a hormone similar to the pituitary gonadotrophin. It is given by injection to treat delayed puberty, undescended testes, premenstrual tension and sterility due to lack of ovulation.
21. **Hysterosalpingogram:** Is the X-ray of the uterus and the tubes.
21. **Intrauterine Insemination (IUI):** Placement of washed sperm into the uterus.
22. **IVF-ET (*In Vitro* Fertilisation - Embryo Transfer):** *In Vitro* Fertilisation-Embryo Transfer is the fertilisation of an ovum outside the body and the transfer of the fertilised ovum to the uterus of a woman.
23. ***In Vitro* Oocyte Insemination:** In IVF, the addition of sperm to a culture dish containing an egg.
24. **Laparoscopy:** Is the surgical procedure to view the pelvis.
25. **Menopause:** Is the time in a woman's life when the cyclic function of the ovaries and menstrual period cease.
26. **Micromanipulation:** Process whereby a single sperm is injected under the egg's shell or directly into the egg to facilitate fertilisation.
27. **Miscarriage:** A miscarriage is the loss of a foetus from natural causes before the twentieth week of pregnancy.
28. **Multiple Pregnancies/ Multifetal pregnancy:** The condition of having more than one foetus in the uterus.
29. **Oocyte Retrieval:** Process of removal of the egg by the technique of aspiration from the ovaries
30. **Ovarian Hyper Stimulation Syndrome:** OHSS is an illness caused by the drugs and hormones given to stimulate the ovaries. Excessive stimulation may cause ovarian cysts and moisture in the chest cavity or the stomach and may result in serious, even fatal, consequences. In mild cases, ovarian enlargement, abdominal distension and weight gain may occur. In severe cases women may also suffer renal impairment, liver dysfunction, thromboembolism. OHSS can result in death.
31. **Ovarian Twisting:** Condition where the stimulated ovary can twist itself cutting off its own blood supply.

32. **Ovulation induction:** Use of female hormone therapy to stimulate oocyte development and release.
33. **PESA (Percutaneous Epididymal Sperm Aspiration) and TESA/TESE (Testicular Sperm Aspiration/ Extraction):** Percutaneous Epididymal Sperm Aspiration Testicular Sperm Aspiration are simplified, minimally invasive outpatient procedures that allow the physician to recover the sperm for fertilisation in patients with obstructive azoospermia (lack of sperm in semen).
34. **Polycystic ovarian syndrome:** Development of multiple cysts in the ovaries due to arrested follicular growth.
35. **Pre-implantation Genetic Diagnosis (PGD):** Pre-implantation Genetic Diagnosis is a technique in which an embryo formed through *in vitro* Fertilisation is tested for specific genetic disorders or other characteristics prior to implantation.
36. **Pre term Birth:** Birth of a baby before 37 weeks (259 days) of gestation (calculated from the first day of the mother's last menstrual period).
37. **Progesterone:** is a hormone produced in the ovaries. It prepares the lining of the uterus for implantation of a fertilised egg and readies the mammary glands to secrete milk.
38. **Still Birth:** A still birth is the loss of a foetus from natural causes after 20th week of pregnancy.
39. **Surrogacy:** Surrogacy is an arrangement in which a woman aggress to carry a pregnancy that is genetically unrelated to her and her husband, with the intention to carry it to term and hand over the child to the genetic parents for whom she is acting as a surrogate.
40. **Surrogacy with Egg Donation:** Surrogacy with egg donation is a process in which a woman allows insemination by the sperm/semen of the male partner of a couple with a view to carry the pregnancy to term and hand over the child to the couple.
41. **Thromboembolism:** A condition in which, blood clot (thrombus), formed at one point in the circulation becomes detached and lodges at another point.
42. **Triple Marker Test:** A blood test used in the pre natal diagnosis of Down's Syndrome, which can be performed at about the 16th week of pregnancy.
43. **Uterine Fibroids:** Benign tumor made up of fibrous and muscular tissue in the uterine wall.
44. **ZIFT (Zygote Intra Fallopian tube Transfer):** ZIFT is the placement of the zygote into the fallopian tube(s).
45. **Zygote:** Fertilised egg prior to first cell division is called zygote.

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ANNEXURE I

This annexure gives a brief overview of the some medical procedures that are a part of ARTs.

In Vitro Fertilisation

IVF consists of several laboratory and medical procedures. Though the finer details might vary from clinic to clinic, women undergoing IVF need to go through the following phases of "treatment".

PHASE 1: Selection of "patients"

Most clinics and hospitals have their own criteria with regard to selection of "patients". The criteria is laid down generally with respect to age and marital status; usually married women under 40 years of age are recommended for "treatment".

PHASE 2: Ovarian Hyper Stimulation (OHS)

The ovaries need to be stimulated to generate more number of eggs and to facilitate this, the woman undergoing IVF is required to take hormones like Clomiphene Citrate daily from the second or third day of menstruation.

Around the 9th day a woman is given hormone injection of hMG (Human Menopausal Gonadotrophin)[1] usually marketed as Pergonal or Humegon. This hormone helps the follicles to mature.

Regular blood and urine tests are taken to check the hormone levels, and to determine the time of ovulation. A daily vaginal ultrasound scan is performed to measure the size of the follicles. When the largest follicle reaches 18mm in diameter, hCG (Human Chorionic Gondatrophin[2]), usually marketed as Pregnyl or Profasi is administered.

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1 Gonadotrophin is any of the several hormones synthesized and released on the pituitary gland that acts on testes or ovaries to promote production of sex hormones and sperm or ova (Oxford concise medical dictionary, 1998)

2 HCG is a hormone similar to the pituitary gonadotrophin. It is given by injection to treat delayed puberty, undescended testes, premenstrual tension and sterility due to lack of ovulation. (Oxford concise medical dictionary, 1998)

This is a hormone that induces ovulation. The entire hormone treatment lasts for about 17 days.

PHASE 3: Egg Retrieval

Within 24-38 hours the egg cells, which have developed, are sucked out of the follicles. This procedure is called egg-cell puncture. One of the techniques through which this is performed is Trans Vaginal Ultrasound Directed Oocyte Recovery (TUDOR). In this, the eggs are harvested through the vagina instead of via laparoscopy, which is a surgical procedure. This procedure is done under local anaesthesia and lasts about 40 minutes[3].

During this phase, sperm from the husband or donor is obtained.

PHASE 4: Treating the gametes

In this phase the sperm and egg cells are treated. The egg cells are kept for a few hours at 37 degree Celsius to incubate/develop.

The semen if provided by the partner is prepared for fertilisation by removing inactive cells and seminal fluid. Or a donor sperm is used. Sperm selection and manipulation take place in this phase.

PHASE 5: Fertilisation

Within a few hours of the above-mentioned process of egg cell puncture, the egg is put together with sperm in a petri dish in a culture medium, for fertilisation to take place.

PHASE 6: Embryo Transplantation

Once the fertilised egg cell splits from a single cell into a two to four to eight-cell stage, it is ready to be transferred into the woman's uterus, where normal gestation follows. This replacement/transfer happens about three days after fertilisation. There is a very short period when egg cells can be fertilised, therefore to improve the chance of a successful pregnancy, more eggs are retrieved, fertilised and usually multiple embryos are replaced.

As more than one embryo is transferred there are chances of multiple pregnancies. In such cases the woman might have to undergo foetal reduction.

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3 Jyotsna Agnihotri Gupta, New Reproductive Technologies, Women's Health and Autonomy, Freedom or Dependency?, Sage Publications, India, 2000

Intra Cytoplasmic Sperm Injection (ICSI)

Intra Cytoplasmic Sperm Injection (ICSI) is an IVF procedure in which a single sperm is injected directly into the cytoplasm of the egg. This technique is used in cases of severe male infertility, including very low sperm count; immotile sperm; and sperm which cannot penetrate the chemical barrier which protects the egg. It is also used in cases where women are unable to conceive due to closed tubes. Sperm can be extracted directly from testis where ejaculation is not possible.

- The ovum is acquired as in IVF. For this the woman undergoes OHS and then the eggs are retrieved.
- Once the eggs are retrieved the sperm is acquired through
- Microscopic epididymal sperm aspiration (MESA): procedure in which spermatozoa are obtained from the epididymis, by either aspiration or surgical excision.
- Testicular sperm aspiration (TESA): procedure in which spermatozoa are obtained directly from the testicle, by either aspiration or surgical excision of testicular tissue.
- The sperm is then selected and manipulated before injecting.
- The sperm is injected into the oocyte under a microscope using micromanipulation devices.
- After this procedure, the oocyte is placed into cell culture and checked on in the following days for fertilisation.
- After fertilisation the embryo is transferred into the uterus for gestation.

Intra Uterine Insemination (IUI)

Intra Uterine Insemination (IUI) is the simplest form of assisted reproduction. It entails sperm being deposited in a woman's vagina close to the cervix. This procedure includes artificial insemination using either the semen of the male partner, typically referred to as artificial insemination husband's sperm (AIH), or artificial insemination by donor sperm (AID). During one menstrual cycle women are inseminated 3-4 times.

- The first step in IUI is hyper stimulating the ovaries through drug treatment to encourage multiple eggs to mature.
- At the appropriate time when ovulation has been induced, prepared sperms are injected into the uterus twice, at 24 and 48 hours after the injection of hCG.
- After insemination is done, hormone (hCG) injections continue till after 12th week of gestation or till the test for pregnancy comes out to be negative pregnancy test.

ANNEXURE II

Side effects and complications of the drugs and procedures

Reporting of adverse side-effects of ART has been in very casual terms and no systematic attempt has been made to document the short- and long-term side effects of these technologies. This is because these side-effects are often considered to be insignificant when weighed against the urge to have one's own child.

However, this negligent attitude towards health risks for women is not specific to the arena of ARTs. Between the 1940s to the 1970s, diethylstilbertrol (DES) was administered to pregnant women in order to prevent spontaneous abortions. But this was done without adequate information regarding the potential side effects of this drug. Disastrous consequences were reported. Daughters of women who took DES suffer cancer of the vagina and cervix at a rate higher than that of daughters of women who did not take DES. Other side effects include increased rates of infertility, spontaneous abortions and ectopic pregnancies. Moreover, even after such a long time span, women who took DES suffer from 40 per cent to 50 per cent higher rates of breast cancer even today. [1]

The Dalkon Shield case is another example of this neglect. The Dalkon Shield was an intrauterine contraceptive device, extensively marketed in the United States in the 1970s. It was inserted in numerous women worldwide, again without being researched thoroughly for potential side effects. Complications, compiled after administration, were numerous. These included severe haemorrhaging, miscarriages, ectopic pregnancies, infertility, mutilated reproductive organs, and even death in some cases.[2]

There is not much literature available on the health risks associated with ARTs. The short-term and specifically long-term side effects of the drugs used and the complications associated with the procedures have also not been studied in depth. A

1 Inmaculada de Melo-Martin, Ethics and Uncertainty: In Vitro Fertilization and Risks to Women's Health, Risk: Health, Safety & Environment 201 [Summer 1998]

2 ibid

WHO Summary Report[3] 1990 defines IVF as experimental and takes the position that no new technology should become an accepted medical practice until it has undergone a thorough and scientific evaluation which has not been the case with ARTs. The U.S. Office of Technology Assessment (OTA)[4] issued the report "Infertility: Medical and Social Choice" listing ovarian hyper stimulation, ectopic pregnancy, miscarriage and pre-term birth as some of the common complications resulting during IVF treatment. The medical procedures used in infertility programmes for oocyte retrieval, foetal reduction and embryo implantation are also associated with a wide variety of complications. In addition to the procedures, the drugs used for treatment also have major side effects. The clinics often overlook or underplay the associated health risks while providing information to the women undergoing these treatments.

Adverse effects of fertility drugs on women's health

"I am only half alive. I became a slave of my body's reaction to fertility drugs – many days I have no energy to do anything."

—A woman undergoing ART procedure

An informal review of medical literature suggests that many physical side effects of ARTs are directly related to the drugs used to stimulate the ovaries to produce more eggs. In the following section, we made an attempt to highlight some of the side effects and complications of the drugs and procedures. However, this annexure is merely a summary of some of the essential health risks posed by ARTs. It is not a comprehensive account of the medical implications of these technologies.

One of the most commonly used drugs in fertility treatment is Lupron. It is often used to " shut down" a woman's ovaries for egg retrieval and has been associated with a range of problems like depression, rashes, chest pain, hot flashes, itching, amnesia, nausea, hypertension, thyroid abnormalities, difficulty in breathing, fainting, weakness, asthma, dimness of vision, bone aches, loss of memory, insomnia and so on. It has United States Food and Drug Administration approval only for the pre-operative management of patients with fibroids and anaemia, and for treatment of endometriosis. Data supporting its use for egg retrieval have not been submitted to any regulatory

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3 WHO Summary Report, "Consultation on the Place of In Vitro Fertilizaton In Infertility Care, WHO Regional Office for Europe, Copenhagen, June 18-22, 1990

4 Inmaculada de Melo-Martin: In Vitro Fertilization and Women's Health, Risk: Health, Safety & Environment 201 [Summer 1998]

5 http://popdev.hampshire.edu/projects/dt/dt33.php

body. Overuse of Lupron may result in osteoporosis. In the U.S., Linda Abend started a National Lupron Victims Network after her sister was hospitalised with seizures along with debilitating bone and muscle pain while taking Lupron in 1991.[5]

Some drugs like Clomid and Pergonal, are used not only in relation with IVF but also to stimulate multiple egg production. This can result in multiple pregnancies which are high risk. One well-known instance in the U.S. was of the Frustaci septuplets. Four of these babies died within four months and the surviving three were left with lifelong disabilities including cerebral palsy and severe developmental disabilities. Although they were not born of IVF, their birth illustrates the problems that result when women are placed on fertility drugs.[6]

Some of the major health risks associated with these drugs are as follows:

Ovarian Hyper Stimulation Syndrome (OHSS)

The most important risk during the phase of artificial stimulation of the ovaries is OHSS. OHSS is caused by the drugs and hormones given to stimulate the ovaries. Excessive stimulation may cause ovarian cysts and moisture in the chest cavity or the stomach and may result in serious, even fatal, consequences.[7] In mild cases, ovarian enlargement, abdominal distension and weight gain may occur. In severe cases women may also suffer renal impairment, liver dysfunction, thromboembolism. OHSS can result in death.[8]

Ovarian twisting

An over-stimulated ovary can twist on itself, cutting off its own blood supply. Surgery is required to untwist or even remove the ovary.

Increased risk of cancers

The question of whether women exposed to fertility drugs face an increased risk of cancers has attracted a lot of attention with many small studies suggesting that women on IVF have a higher risk of cancers of the breast, ovary and uterus compared with the numbers expected among women of the same age in the general population. Some studies assert that ovulation induction may be a risk factor for certain types of hormone-dependent cancers. Researchers have associated excessive estrogen

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6 Janice Raymond The production of fertility and infertility: East and West, North and South, in Women as Wombs, Harper Collins 1993

7 Jyotsna Agnihotri Gupta, New Reproductive Technologies, Women's Health and Autonomy,: Freedom or Dependency?, Sage Publications, India, 2000

8 Inmaculada de Melo-Martin: In Vitro Fertilization and Women's Health, Risk: Health, Safety & Environment 201 [Summer 1998]

secretion with ovarian and breast carcinoma, and gonadotrophin secretion with ovarian cancer.[9] Studies indicate that hormones play a major role in the development of several human cancers. The ability of hormones to stimulate cell division in certain organs, such as the breast, endometrium, and the ovary, may lead to the accumulation of random genetic errors that ultimately produce cancer. Hence, techniques such as IVF that rely on massive doses of hormones may be quite dangerous.[10]

The drug Tamoxifen used extensively in the treatment of breast cancer carries a slightly increased risk of endometrial cancer. As it has similar properties to the fertility drug Clomiphene, there is a concern that women who use Clomiphene for long periods might have an increased risk of endometrial cancer. Also many women who seek fertility treatment do not ovulate regularly on their own and face an increased risk of endometrial cancer owing to the imbalance between estrogen and progesterone levels.[11]

The following table summarises some of the drugs which were used for ovarian stimulation /egg extraction and their long-term effects

S.No	Drug	Side Effects
1.	Fertomid	Ovarian enlargement, hot flushes, abdominal discomfort, birth defects, ovarian hyperstimulation syndrome, multiple pregnancy and ectopic pregnancy, hair thinning, visual blurring, breast discomfort, depression, ocular toxicity. *Ref: Monthly Index of Medical Specialities , MIMS, Vol 26 Number 2, Feb 2006*
2.	Profasi	Oedema, headache, mood changes, tiredness, sensitivity reactions, sexual precocity, ovarian ascities, pleural effusion, ovarian cyst rupture, multiple births, arterial thromboembolism, depression, restlessness. *Ref: Hormones, Trophic Hormones & Related Drugs, MIMS, Volume 26 Number 3, March, 2006*

9 See, e.g., John Jarrel et al., Adverse Health Effects of Drugs Used for Ovulation Induction, New Reproductive Technologies and the Health Care System.

The Case for Evidence-Based Medicine, Royal Commission on New ReproductiveTechnologies (1993); cited in de Melo-Martin: In Vitro Fertilization and Women's Health, Risk: Health, Safety & Environment 201 [Summer 1998]

10 Inmaculada de Melo-Martin: In Vitro Fertilization and Women's Health, Risk: Health, Safety & Environment 201 [Summer 1998]

11 www.victoriafertility.com

3.	Pubergen	Oedema, headache, mood changes, tiredness, sensitivity reactions, sexual precocity, ovarian hyperstimulation or enlargement, ovarian cyst rupture, multiple births, arterial thromboembolism, depression, restlessness. *Ref: Hormones, Hyper & Hypo- glycaemics, MIMS, Volume 26 Number 3, March, 2006*
4.	Metformin	Nausea, vomiting, gas, bloating, diahorrea and loss of appetite, lactic acidosis, general malaise, fatigue and occasional aches, gastrointestinal disturbance, vitamin b12 mal absorption, anemia, liver or kidney problems, hair loss, lactic acidosis, bile abnormalities. *http://www.medicinenet.com/metformin/article.htm*
5.	Cetrotide Serum	Injection site reactions, ovarian hyperstimulation syndrome, headache, nausea, elevated enzymes (e.g., alkaline phosphates) *Ref: Hormones, Hyper & Hypo- glycaemics, MIMS, Volume 26 Number 3, March, 2006*
6.	Clomiphene Citrate	Include hot flushes, blurring of vision, abdominal discomfort, ovarian enlargement, nausea, vomiting, breast soreness, depression and allergic dermatitis. *Ref: Hormones, Trophic hormones & related drugs MIMS, Volume 26 Number 3, March, 2006*
7.	Gonal – F	Sensitivity reactions, multiple pregnancy, thromboembolism, Acne, injection site irritation, fatigue, breast tenderness, ovarian enlargement or cysts, G-I upset, headache, distention, gynacomastia., *Ref: Hormones, Trophic hormones & related drugs, MIMS, Volume 26 Number 3, March, 2006*
8.	Gonotrop F	OHSS with pulmonary and vascular complications, ovarian enlargement or cysts or rupture, abdominal pain), local reactions, multiple pregnancies. *Ref: Hormones, Trophic hormones & related drugs,MIMS, Volume 26 Number 3, March, 2006*
9.	Pergonal- 75	Sensitivity reactions, ovarian enlargement or cysts or rupture, multiple pregnancies, abdominal pain, G-I upset, hemopritoneum. *Ref: Hormones, Trophic hormones & related drugs, MIMS, Volume 26 Number 3, March, 2006*

10.	Pregnyl	Headache, tiredness, changes in mood, irritation in area of use, abnormal enlargement of breasts in men (gynaecomastia), over stimulation of the ovaries causing production of many ova in the woman, excessive fluid retention in the body tissues, resulting in swelling (oedema), pregnancy with two or more foetuses. *Ref: Hormones, Trophic hormones & related drugs, MIMS, Volume 26 Number 3, March, 2006*
11.	Puregon	Over stimulation of the ovaries causing production of many ova in the woman, blood clots in the blood vessels (thrombosis) that may detach and travel in the circulation to another area of the body (thromboembolism), pregnancy with two or more foetuses, pain, soreness or bruising at the injection site. *http://www.appco.com.au/appguide/drug.*
12	Human Menopausal Gonadotrophin (HMG)	Weariness, mood changes, hot flushes, nausea and headaches, increased pelvic pressure/pain, high risk of miscarriage, ovarian enlargement, abdominal pain. *www.bchealthguide.org/kbase/topic/detail/drug/*

Risks with the procedures

Apart from the drug-related side effects and risks, there are also risks or surgical complications in relation to the various procedures that are a part of IVF. Procedures normally used for egg retrieval are laparoscopy and ultrasound-guided oocyte retrieval or Transvaginal Ultrasound Aspiration. Although there are few data about the hazards associated with these two procedures, the general risks from laparoscopy include bleeding from the ovary or from adjacent pelvic structure and abdominal wall, and pelvic infection is also common. Laparoscopy is conducted under anaesthesia and the associated risks are allergic rashes, temporary paralysis, vomiting and even, in more extreme cases, death. Patients who have had previous surgery (and this applies to many requiring ARTs) may have bowel adhesions. This increases the risk of injury to the bowel.

Another risk is that the carbon dioxide gas that is placed into the abdomen during laparoscopy may not all be expelled at the end of the operation; again this is more common in patients with adhesions. This may provide some discomfort under the ribs or in the shoulder.

Transvaginal Ultrasound Aspiration might cause undetected bleeding. Symptoms should be noted within six hours and nursing observation must be carried out for this period of time.

Another procedure used for egg retrieval, Transvaginal Ultrasound Directed Oocyte Recovery (TUDOR), can result in pain, bleeding, or damage to internal organs, swelling in the pelvic area and infections in the vagina and bladder.

Ectopic pregnancies

Up to eight per cent of pregnancies achieved by IVF may be ectopic, with the consequent dangers of haemorrhage and even death. Emergency laparotomy may be necessary, with its attendant risks. However, most "patients" are closely monitored with ultrasounds and ectopic pregnancies are identified before they can cause complications. Fewer ectopic pregnancies are seen in GIFT/ZIFT. Occasionally women can have multiple ectopic pregnancy in two different sites which may prove dangerous.[12] Studies also show that five to seven per cent of all IVF pregnancies implant outside the uterus.[13]

Multiple gestation pregnancies

Multiple gestation pregnancies have been found to occur in up to 25 per cent of ART pregnancies while they occur in only two per cent in the general population.[14] Multiple-birth pregnancies increase the danger of miscarriages, caesarean sections, early labour, and placental dysfunction. High order multiple gestation pregnancies are associated with an increased risk of pregnancy loss, premature delivery, abnormalities in the infant, pregnancy-induced hypertension, haemorrhage, and other significant maternal complications.

Spontaneous Abortions

The rate of spontaneous abortion increases with increasing age of the mother and in multiple pregnancies, especially with three or four foetuses. 20 – 35 per cent of such pregnancies result in spontaneous abortions.

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12 A case of simultaneous tubal-splenic pregnancy after assisted reproductive technology. Fertility andSterility, 2005 Apr; 83(4):1042

13 Medical Research Institute, Society of Assisted Reproductive Technology, The American Fertility Society, In Vitro Fertilization/ Embryo Transfer in the United States: 1988 Results from the National IVF-ET Registry, Fertility and Sterility 1990

14 World Health Organization (WHO), Recommendations on the Management of Services for in Vitro Fertilization from the WHO 1990,cited in Inmaculada de Melo-Martin: In Vitro Fertilization and Women's Health, Risk: Health, Safety & Environment 201 [Summer 1998]

Risks of foetal reduction

Multiple gestation pregnancies are a complication of infertility drugs and treatments. The continued use of fertility drugs and the implantation of more than one embryo to improve success rates can pose a risk to the mother and foetus. Multiple gestation pregnancy is one such complication. Foetal reduction is used to selectively terminate foetuses in multiple gestation pregnancies. A saline solution is injected into the uterus to abort some foetuses. This can cause uterine bleeding, infection, premature labour and loss of all foetuses.[15] One hazardous technique is used to correct a problem which is the result of the use of another faulty technique.

Risks of multiple pregnancies

Obstetrically, carrying two babies places greater pressures on the pregnant woman. There is an increased risk of miscarriage, obstetric complications, premature deliveries and birth complications. Maternal morbidity is seven times higher in multiple pregnancies than in singletons.[16]

Risks on Children

However, the adverse side- effects of ART are not limited to women but also affect children born through these procedures. Most important risk to the baby results from multiple pregnancy. The Rate of premature delivery increases from 7 per cent with a single gestation to 41 per cent with twins and to 93 per cent with triplets. Thus many IVF programs have now reduced the number of embryos transferred. The risk of congenital and chromosomal anomalies seems similar in IVF and naturally conceived children. This risk is not increased after transfer of thawed embryos but is influenced by female age and multiple pregnancies.

Concerns have been raised about the safety of ICSI in two areas: genetics and child development. Men with abnormal sperm production have an increased rate of sex chromosome anomalies, presumably increasing the potential for transmission of sex chromosome anomalies to the offspring. Another concern is child development. Though no difference has been noted between IVF and general population up to the age of 13 years however a small study from Australia suggests that the Bayley score at one year is statistically significantly lower after ICSI conceived compared with IVF conceived and naturally conceived children.

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15 Janice Raymonds, The production of fertility and infertility: East and West, North and South, in Women as Wombs, Harper Collins 1993

16 Wimalasundera RC, Trew G, Fisk NM., Reducing the incidence of twins and triplets in Best Pract Res Clin Obstet Gynaecol. 2003 Apr; 17 2):309-29.

Sama- Resource Group for Women and Health, is a Delhi based women's group working from a larger perspective that links women's well-being with issues not only of health, but also those integrated with livelihood, violence (societal, familial, communal and medical), and all other issues that affect people's lives, especially those of women. Sama works closely with tribal, dalit and other marginalised communities and has made interventions through various activities like Community Based Training, Action Research, Advocacy and Material Production.
Sama is an active member of Jan Swasthya Abhiyan (Indian Chapter of People's Health Movement) and is part of the Autonomous Women's Movement.

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